The lived experience of return to paid work following a brain injury

Submitted for the Degree of Doctor of Philosophy
At the University of Northampton

Year
2015

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Acknowledgements

I would like to thank my supervisory team: Professor Annie Turner, Associate Professor Jackie Parkes and Professor Jackie Campbell for their guidance throughout the last five and a half years.

I would also like to thank Professor Carol Phillips, Deputy Dean, School of Health, for her belief and her ongoing confidence in me and would like to acknowledge the considerate support provided by David Watson, Research Student Manager. To my many friends and colleagues, there are too many of you to name but you know who you are, I am in your debt for the ongoing faith that you have had in me.

I should also like to thank all of the participants who took part in my research and gave up their time to share their experience with me as without them I could not have achieved any of this.

Thank you also to the United Kingdom Occupational Therapy Research Foundation and to Irwin Mitchell Solicitors for awarding me the Irwin Mitchell Research Award in 2011, which has been a great asset and allowed me to buy time away from work to progress my study. In addition to the Award, I would also like to acknowledge the ongoing support and current and future collaborations with Irwin Mitchell.

On a personal note I would like to thank my beautiful family. My Dad for just being there and always consistently confirming that I can achieve what often feels unachievable. Thanks to my daughter Emily for her tender and loving support. Thanks to my son Daniel for his technical and devoted support. I have no idea how I could have completed this PhD without my husband Phil, who as ever has been my more balanced and sensible half as well as my best friend, mentor and entertainer.

I would like to dedicate this thesis to my Mum and to my brother Billy who I know would have wanted to be here to see me complete it. I just know wherever you are that you will be smiling and saying something very grounded and funny!

Abstract

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Introduction

In Western industrialised societies and cultures paid work is valued and it is generally accepted that being in paid work is good for an individual's health and allows them to be less dependent on others. Only one third of the brain injury population are believed to return to paid work. Those that return do not return at the same level or for the same hours and often for less pay. Paid work provides benefits such as a financial income, improved emotional wellbeing, increased self-esteem, more independence, social roles and a sense of identity. Those unable to return to paid work are more likely to have poorer general and mental health and to become depressed. Rehabilitation outcome can be viewed as successful when it results in return to paid work post injury, but the cost of rehabilitation is significant. Life expectancy following a brain injury is often unaffected and current return to paid work success in the United Kingdom is poor. The factors involved in return to paid work following a brain injury warrant exploration because of the social and financial consequences and the majority of these individuals being of working age.

In this research I explored the factors which impact on the return to paid work of individuals following a brain injury with the aim of improving return to paid work rehabilitation for people with an acquired or traumatic brain injury.

Method

I used a qualitative, descriptive phenomenological research approach, developed by Giorgi (1985), to systematically recruit, collect and analyse data from twenty seven participants. Sixteen of the participants had experienced either a moderate to severe traumatic or acquired brain injury and had returned to paid work. Eleven of the participants were employers who had been involved in the return to paid work of similar individuals following a brain injury. All participants were interviewed face to face and their lived experiences explored with them. Descriptive phenomenological analysis of all of the data was used to establish a general situated structure and story of the phenomenon of return to paid work following a brain injury.

Findings

Following phenomenological analysis of the general situated structure, the deeper meaning of the phenomenon was explored using free imaginative variation, responsive reflective writing and categorial intuition. Four themes emerged from the structure: occupational needs; experiencing loss, grief and adjustment; self-identity; and social inclusion and return to the workplace. A return to paid work conceptual framework was developed from evaluation of the research findings.

Discussion

The emergent conceptual framework to facilitate return to paid work rehabilitation of individuals following acquired or traumatic brain injury discusses a new and different way to help these individuals, their employers, professionals and relevant others to plan and manage return to paid work following a brain injury. The framework advocates that individuals should have their occupational nature, drive and needs acknowledged and assessed. Their losses also need to be acknowledged and addressed, grief recognised as well as challenges to their self- identity. Social inclusion in the workplace needs to be promoted in addition to support provided to facilitate adjustment to injuries and self-identity.

Conclusions

Current practice needs to change to prevent individuals from missing essential information about brain injury and rehabilitation. Vocational rehabilitation services would be enhanced by inclusion of assessment of occupational needs, loss and grief counselling and the provision of coping strategies to inform employers and individuals following a brain injury regarding how to manage loss and adjustment in the workplace. Addressing changes in self-identity would help individuals come to terms with their changing identity. Government legislation could also be developed that could guarantee the provision of vocational rehabilitation following a brain injury and the delivery of education to tackle discrimination and social exclusion in the workplace.

Contents

Chapter 1 Introduction

1.1 Introduction

This first chapter begins with an introduction to the PhD research topic 'The lived experience of return to paid work following a brain injury', and my background as the researcher. It then goes on to provide a rationale in relation to why this is such an important area to research, the wider research context and my perspective as an occupational therapist. The chapter concludes by establishing the research title, aims and objectives, and by presenting the structure of the overall thesis.

1.2 An introduction to return to paid work following a brain injury

It is generally accepted that being in paid work is good for individuals' health, however return to paid work has been reported as limited to only one third of the brain injury population (Waddell and Burton, 2006; Barnes and Holmes, 2007). Unfortunately, following a brain injury those individuals that return to paid work often do not return at the same level, for the same hours or for the same pay, and are reported to be less involved in working with others than the general population (Gamble and Moore, 2003; Winkler *et al*., 2005).

Success rates of return to paid work for individuals following a brain injury vary, and unemployment rates for persons following a traumatic brain injury are reported to be considerably higher than the general population (Sabello, 2014). Barnes and Holmes (2007) claim that one third of the brain injury population return to paid work, however Sabello (2014) established that, following a traumatic brain injury, 40-90% of individuals are unemployed one year after their injury, and that often they do not return to work full time nor hold high level positions. The findings of Sabello (2014) are consistent with findings in the Netherlands where Van Velzen *et al.* (2009a) reported that, following a systematic review of 49 studies including individuals following traumatic acquired brain injuries, 40.7% of them returned to work after one year and 40.8% after two years. A similar picture is also evident in Australia and New Zealand where the return to work rates of 1010 individuals following acquired brain injuries had a reported median of 46% of those participants returning (Athanasou, 2003).

It has been established that return to work within the traumatic brain injury population is unlikely if it has not been achieved within one year following injury (Kendall *et al.,* 2006). Despite the apparent poor return to work success rates of these mostly working age people, the longer term picture is that over 80% of individuals sustaining a severe brain injury have been reported as unemployed after five years (Ross, 2007). Unfortunately without intervention "few of them will have a chance to work again" (Ross, 2007, p.190). This suggests that even for those individuals that manage to return to paid work following a brain injury, it is by no means certain that they will sustain their return.

1.3 The researcher's background

Motivation and inspiration to carry out this PhD research came from my continued personal and ongoing research and practice journey in the study of individuals following a brain injury. My journey started 30 years ago, when I was working as a final year occupational therapy student and came into contact, for the first time, with a young person who had experienced a brain injury. Since then I have worked with a large number of individuals following brain injuries across various rehabilitation settings within the United Kingdom, and for very short periods of time in Australia and Canada. Throughout this time it has become evident that very few individuals following a brain injury are able to return to paid work despite intensive rehabilitation from multiple professionals often over lengthy periods of time. It was after completion of my MSc primary research exploring occupational therapists' perceptions and management of aggression with adults following a brain injury, that I became more acutely aware of the difficulties faced by individuals following brain injuries, their families and carers (Beaulieu, 2007). Following my MSc research and training, I became more focussed on researching ways that rehabilitation following a brain injury could be improved.

1.4 The research rationale

It has been highlighted that it is incredibly difficult following a brain injury to return to paid work due to resulting psychosocial, cognitive and/or physical deficits, which often have a negative effect on an individual's ability to seek or maintain employment (Vandiver *et al.,* 2003; Schonbrun *et al.,* 2007).

Webb *et al.* (1995), following a longitudinal survey, suggested that paid employment is the strongest contributor to improved quality of life, and 12-24 months after a brain

injury that a poorer quality of life was reported. Despite Webb *et al.'s* (1995) findings being from the USA, and having potentially limited cultural generalisability, they do support the research rationale. The most significant associations with quality of life reported by their 293 participants were their resulting impairments and employment changes. Return to paid work appears to be associated with improved quality of life by providing better opportunities for these individuals.

The need to address barriers impacting these individuals getting back or into paid work has been prioritised by the Government in the United Kingdom, and some individuals following a brain injury believe that until they are able to return to paid work that their recovery is incomplete (Gamble and Moore, 2003; Winkler *et al.,* 2005; Department for Work and Pensions and the Department of Health and the Health and Safety Executive, 2005). A better understanding of how individuals following a brain injury currently experience return to paid work is needed. Increased understanding of solely the experiences of individuals following a brain injury however would only be part of the picture, as if future rehabilitation services and return to paid work rates are to be improved the current return to paid work experiences of employers also need to be better understood.

The United Kingdom spends £13 billion a year on health-related benefits and, following a Review of Sickness Absence, prioritised trying to reduce sickness absence, and to introduce ways of supporting individuals with health conditions to both retain and return to paid work (Black and Frost, 2011). This prioritisation, whilst acknowledging weaknesses in the United Kingdom system, aimed to provide ways of reducing both burdens to these individuals and societal costs (Black and Frost, 2011). There is a need to address the loss of and impact on economic productivity, the significant financial, health and social burdens for individuals following a brain injury and society. These individuals are experiencing a poor quality of life post injury and unable to contribute to society despite significant spending on hospital care, rehabilitation and sickness absence (Webb *et al.,* 1995; Ownsworth and McKenna, 2004; Black and Frost, 2011). Research evidence is needed to better understand the current barriers and success factors of returning to paid work following a brain injury. This evidence is needed to not only improve their health, quality of life and rehabilitation, but also to address the financial balance of ongoing

sickness absence and welfare benefit costs versus these individuals being able to contribute to future taxable income (Black and Frost, 2011).

1.5 The wider research context

A more detailed background to the research is provided in chapter two. It is important however to introduce within this first chapter the wider context in relation to the advantages and disadvantages of working and return to paid work risk assessment following a brain injury.

1.5.1 Advantages and disadvantages of working following a brain injury

Paid work is a "major activity throughout most of life for most adults in Western society" (Winefield *et al.*, 2002, p.1). Gainful employment is valued in industrialised societies and cultures, and impacts on individual identity and status. The other side of this "Western institutionalisation of work" is that not to have work is to have an undefined identity and status, to have an uncertain future and to be seen as dependent on others (Winefield *et al.*, 2002, p.2).

Nightingale *et al.* (2007) carried out a systematic review in Australia, which researched early prognostic factors for return to work after traumatic brain injury. They concluded that work provides benefits such as improved emotional wellbeing, increased self-esteem, independence and a sense of identity. It has also been suggested that work provides individuals following a traumatic brain injury with motivation to leave their house in the morning, and the opportunity to meet new friends (Wehman *et al.,* 2005). Paid work is generally seen as essential for financial independence, to fulfil psychosocial needs and central to social status (Waddell and Burton, 2006).

Evidence has also established that unemployment is harmful to general and mental health, and that it "is linked to higher medical consultation, medication consumption and hospital admission rates" (Waddell and Burton, 2006, p.2). Radford *et al.* (2013) believe that individuals following a brain injury, who do not return to work, are more likely to be depressed, and Van Velzen *et al.* (2012) have suggested that cognitive and physical tiredness, a lack of knowledge and support from employers and colleagues may be factors that stop return to paid work taking place. It is believed that failure to return to work following a brain injury has been associated with premorbid factors such as educational

level, psychiatric history, a violent cause of injury and injury severity, but little is known about the rehabilitation provided to these individuals.

The balance of evidence suggests that paid work is generally good for health and wellbeing, and can provide discipline "in terms of the rhythms of the working day" (Strangleman, 2012, p.417). It has to be acknowledged however that provisos exist in relation to the beneficial effects of paid work, such as the nature and quality of the of work and the social context (Waddell and Burton, 2006).

1.5.2 Return to work risk assessment

Currently there is no work risk assessment tool in the United Kingdom for cognitively impaired individuals, no guidelines for evaluating work readiness or any unique neuropsychological test to predict return to paid work following a brain injury. Stergiou-Kita *et al.* (2009) in Canada, although of limited help, explored how 10 occupational therapists evaluated work readiness. These therapists reported assessing individuals' occupational capacity and building a shared understanding of work readiness with employers and insurers, although interestingly not the injured individuals. McNamee *et al.* (2009) recommend that the rehabilitation focus must be on employment outcomes in paid jobs, and those individuals following a brain injury must not settle for sheltered unpaid work. Assessment in live work situations is considered to be critical when making return to paid work predictions due to some individuals post injury having difficulty generalising new learning to different contexts and environments.

Little appears to be known about the content of vocational rehabilitation interventions and the experiences of individuals following a brain injury returning to paid work. In the United Kingdom Radford *et al.* (2013), when determining whether a traumatic brain injury specialist vocational rehabilitation intervention was more effective for 94 participants at work return and retention 12 months after injury than usual care, established that specialist vocational rehabilitation was better than usual care. In Canada Stergiou-Kita *et al.* (2012), following a qualitative synthesis representing the views of 50 individuals following a traumatic brain injury, suggest that on trying to return to work individuals risk failure whilst trying to adapt to changes. Furthermore, Stergiou-Kita *et al.* (2012) suggested that the timing of return to work is important, although their study

participants' injury severity ranged from mild to severe so could have influenced their results.

Return to paid work is clearly viewed as an important measure of successful rehabilitation (Winkler *et al.,* 2005). Despite this however, little appears to be known about many brain injury consequences, their assessment and return to paid work rehabilitation, let alone predicting and facilitating successful return to paid work.

Current poor return to paid work outcomes following a brain injury appear to be resulting in significant financial and social burdens for both individuals and for society (Ownsworth and McKenna, 2004). Considering individuals' life expectancy is unaffected following a brain injury, the cost of rehabilitation significant, and that for most individuals returning to paid work can be impossible, the factors involved in their return to paid work warrant further research.

1.6 The researcher's perspective as an occupational therapist

As an occupational therapist my professional philosophy is that meaningful occupations, including paid work, are essential to health. Occupation refers to the "practical and purposeful activities that allow people to live independently and have a sense of identity and could be essential day-to-day tasks such as self-care, work or leisure" (COT, 2015b, p.1). Meaningful occupation is important in maintaining the wellbeing of individuals, and if participation in occupation is interrupted it can result in a breakdown of habits, physical and emotional deterioration and individuals' abilities to perform in their everyday lives (Keilhofner, 1997).

It could be that successful return to paid work may be associated with factors other than hours worked or pay earned, and could be that when individuals are meaningfully occupied that they have a positive sense of identity (Levack *et al.,* 2004). Individuals need to realise their creative potential and the connection between creativity and their health and wellbeing (Molineux, 2004). Yerxa (1998) believes that society is failing to recognise the impact of the loss of occupational roles on health. I agree that a better understanding of the part that returning to paid work plays in these individuals' lives and how they go about achieving this is needed, and advocate a need to better understand the potential relationship of occupation to their feelings of self-efficacy. Such research findings could inform future practice regarding the best way to intervene when individuals "have lost

the building blocks of occupation" due to disability, and provide knowledge of how paid work could become more accessible and engaging for individuals following a brain injury (Yerxa *et al.,* 1989, p.12). If paid work is not possible potentially other occupations could provide these individuals with similar life satisfaction and an improved quality of life. A better understanding of the meaningful occupation of paid work and the journeys of individuals and employers following a brain injury is needed if future rehabilitation and return to paid work rates in the United Kingdom are to be improved.

1.7 The research title, aims and objectives

From the above background, rationale, context and my research perspective the following research title, aims and objectives have been established to address this research need.

1.7.1 The research title

The lived experience of return to paid work following a brain injury.

1.7.2 The research aims

To explore and understand the factors which impact on return to paid work from the perspective of individuals following a brain injury and employers in England, and to subsequently improve return to paid work rehabilitation for people with an acquired or traumatic brain injury.

1.7.3 The research objectives

I established the following four objectives to address the research aims:

1. To critically appraise the background and evidence-based literature related to brain injury and return to paid work.

2. To collect and analyse data of the return to paid work experiences of individuals following a brain injury to establish potential barriers and success factors (phase one).

3. To collect and analyse data from employers who have experienced the return to paid work of individuals following a brain injury to establish potential barriers and success factors (phase two).

4. To evaluate the research findings to inform future practice and to improve return to paid work rehabilitation for people with an acquired or traumatic brain injury.

1.8 The structure of the thesis

This thesis is presented in six further chapters. Chapter two provides a detailed background and a review of the evidence based context relevant to the research. As the aim of the research was to explore the lived experiences and phenomenon of return to paid work of individuals following a brain injury, I felt that a descriptive phenomenological method was most suited. After careful consideration I decided to use Giorgi's (2000a) descriptive approach as the method for this research. Chapter three therefore justifies and presents the descriptive phenomenological approach used to underpin the research data collection process and analysis. Chapter four presents the practical data collection and analysis steps that were taken using Giorgi's (2000a) phenomenological approach, and its application. Chapter five presents both the phase one and two descriptive research findings and the resulting general description of the situated structure of return to paid work of individuals following a brain injury from both phase participants' experiences. Chapter six discusses the essence and meaning of the phenomenon, and the four final themes that emerged. Chapter seven presents a conceptual framework that I subsequently developed to facilitate return to paid work rehabilitation of people with acquired or traumatic brain injury, the research conclusions, and recommendations regarding how the findings can inform future return to paid work rehabilitation and services.

1.9 Conclusion

This chapter has introduced that it is incredibly difficult following a brain injury to return to paid work due to resulting psychosocial, cognitive and/or physical deficits (Vandiver *et al.,* 2003; Schonbrun *et al.,* 2007). This research is needed as, despite intensive rehabilitation from professionals often over lengthy periods of time, return to paid work is currently believed to be limited to only one third of the brain injury population, and return to paid work success rates in the United Kingdom vary considerably (Barnes and Holmes, 2007; Sabello, 2014). Ways of reducing the financial and social burdens of these individuals and societal costs need to be identified. These individuals not only currently experience a poor quality of life post injury, but are also unable to contribute to society in the longer term (Webb *et al.,* 1995; Ownsworth and McKenna, 2004; Black and Frost, 2011).

Being able to work provides benefits such as improved emotional wellbeing, increased self-esteem, more independence and a sense of identity, but following a brain injury those unable to return to work are more likely to have poorer general and mental health and to be depressed (Waddell and Burton, 2006; Nightingale *et al.,* 2007; Radford *et al.,* 2013).

Currently there is no work risk assessment tool, and little is known about the content of vocational rehabilitation interventions and the experiences of individuals following a brain injury returning to paid work (Stergiou-Kita *et al.,* 2009). Return to paid work outcome is viewed as an important measure of successful rehabilitation, but currently in the United Kingdom the cost of rehabilitation is significant. Due to individuals' life expectancy being unaffected following a brain injury, the factors involved in their return to paid work warrant further research.

If future rehabilitation and return to paid work rates in the United Kingdom are to be improved, there is a need to explore and better understand the meaningful occupation of paid work, and the experiences of individuals and employers following a brain injury to identify factors that impact successful return to paid work rehabilitation.

Chapter 2 Background and context

2.1 Chapter introduction

This research background and context chapter is presented in two parts.

Part one uses four separate sections to provide a detailed background in relation to the necessary definitions and explanations of the research terms, and the context in the United Kingdom. Part one continues with an exploration of the occupational therapy perspective on health and the potential relevance of occupational theory. Part one concludes with a review of the current occupational therapy context in the United Kingdom.

Part two provides a review of the evidence base and critically synthesises and establishes a baseline of existing knowledge in relation to the research. A review of the literature is presented within this chapter to provide a logical thesis structure, and make it easier for the reader to read, however I carried out the literature review following completion of all data collection and analysis. This was to abide by the methodological rule of epoche, to help me to bracket and minimise any bias and beliefs prior to data collection beginning, and to avoid alternative interpretations of the data (Giorgi, 2000b).

Part one

2.2 Definitions and explanations of the research terms

This first section of part one provides the necessary definitions of and explanations about the research terms commonly used in relation to brain injury, work and the current ability to predict return to work following a brain injury.

2.2.1 Brain injury

Head injury is the most common cause of death and disability in people aged one to 40 years in the United Kingdom and 1.4 million people each year, following a head injury, attend Accident and Emergency departments in England and Wales (NICE, 2014). It has been reported that traumatic brain injury is a leading cause of disability in young people, with the highest incidence of injury in those aged between 15-24 years, which are considered to be formative working years (Willmott *et al.,* 2014). Within the United Kingdom, 275 in every 100,000 individuals are estimated to sustain an acquired brain injury requiring admission to hospital each year (Ralph and Derbyshire, 2013). The Scottish Intercollegiate Guidelines Network (2009) claim that annual attendance at Accident and Emergency departments with a head injury in the United Kingdom is 6.6%, and approximately 1% of those following injury will be admitted to hospital. In the United Kingdom there are approximately 500,000 people (aged 16-74) living with long term brain injury disabilities with 85% classified as minor, 10% moderate and 5% severe (Headway, 2009). Men are known to be two to three times more likely to have an injury than women, increasing to five times more likely between 15-29 years (Headway, 2009).

2.2.2 Different types of brain injury

Several terms are used synonymously to describe a brain injury such as head injury, traumatic brain injury or acquired brain injury, therefore it is important to explain and clarify what each of these terms mean. Brain injury is generally defined as an injury to the brain caused by trauma or disease, and can be either an acquired or traumatic injury.

Head injury has been defined as any “trauma or external force to the head other than superficial injuries to the face” (NICE, 2014, p.6). The Scottish Intercollegiate Guidelines Network (2009) define a head injury as where there is a history of a blow to the head, presence of a scalp wound, or where there is evidence of an individual having altered consciousness after a relevant injury.

Traumatic brain injury is an injury to the brain caused by a trauma to the head, and is defined as "a traumatically induced structural injury and/or physiological disruption of brain function as a result of an external force" (NICE, 2014, p.31). There are many causes of traumatic brain injury such as road traffic accidents, assaults, violence, military conflict, falls, accidents at home or work, and sport or leisure injuries. Around one million individuals in the United Kingdom sustain a traumatic brain injury each year, and up to 150,000 have moderate or severe injuries (Radford *et al.,* 2013). Traumatic brain injury is three times more common in men, adolescents and young adults (Shames *et al.,* 2007). Traumatic brain injury is often followed with one or several of the following clinical symptoms: a loss or altered level of consciousness, a loss of memory for events immediately before or after the injury, confusion, disorientation, slowed thinking or neurological deficits such as muscle weakness, loss of balance, visual changes, sensory loss or aphasia (NICE, 2014). Traumatic brain injury may lead to secondary complications such as subsequent cerebral contusions, haemorrhage and increased intracranial pressure (Shames *et al.,* 2007). Traumatic brain injury has been identified as causing a dramatic loss and impact on economic productivity as it usually affects individuals of working age who are in a productive stage of their life (McNamee *et al.,* 2009). The societal cost of traumatic brain injury has been estimated at £1.9 billion each year due to lost work time and welfare benefit claims (Radford *et al.,* 2013).

Acquired brain injury is damage to the brain which is non-degenerative, and can be due to internal or external causes. Acquired brain injury covers all situations in which any brain injury has occurred since birth, and includes traumatic brain injury as well as tumour, stroke, brain haemorrhage, anoxia, aneurysm, embolism, meningitis, poisoning or encephalitis. Acquired brain injury subsequent effects are often very similar to those experienced following a traumatic brain or head injury (Headway, 2009). Each year over one million people attend hospital as a result of acquired brain injury, of which around 100,000 are believed to be left with significant disability.

Following a head injury, traumatic brain injury or acquired brain injury, whether or not the individual was actually unconscious, they may experience a state where they seem to be aware of things around them but where they are confused and disorientated. Individuals may be unable to remember everyday things or conversations, and often will do or say bizarre things. This state is called post-traumatic amnesia, and is a stage

through which individuals pass post injury. The length of post-traumatic amnesia and/or loss of consciousness are important as they indicate the severity of the brain injury sustained (Headway, 2009). Post-traumatic amnesia is usually defined as the time between receiving a brain injury and the return of normal continuous memory. Post-traumatic amnesia includes any periods of unconsciousness, confusion and disorientation (King *et al.,* 1997). Both the length of time of post-traumatic amnesia and the Glasgow coma scale are internationally considered to be effective predictors of diagnosis and outcome following a brain injury (Balestreri *et al.,* 2004).

Russell and Smith (1961) established an international brain injury severity classification based on post-traumatic amnesia experienced by individuals and established the following guide to uniformly aid diagnosis. A mild brain injury classification was established for post-traumatic amnesia experienced for less than an hour, a moderate brain injury for post-traumatic amnesia between one and 24 hours, a severe injury for between one and seven days and a very severe injury lasting more than seven days. This severity classification is used as a general measure; however it does rely on accurate assessment and documentation of post-traumatic amnesia.

Another important and commonly used predictor of outcome after head injury is the Glasgow coma scale (Balestreri *et al.,* 2004). This scale and outcome measure was introduced by Teasdale and Jennett (1974), and it assesses an individual's eye opening, verbal responses and motor responses following injury. Using the Glasgow coma scale a brain injury is considered to be mild if the individual has a Glasgow coma scale score of 13-15, moderate with a score of 9-12 and severe if the score is 8 or less (Scottish Intercollegiate Guidelines Network, 2009). The Glasgow coma scale is internationally the most clinically and research used neurological assessment measure following a head injury. Both an individual's age and their Glasgow coma scale score on hospital admission are considered to be important predictors of outcome after a brain injury (Balestreri *et al.,* 2004).

2.2.3 The consequences of a brain injury

Brain injury can cause significant physical, cognitive, behavioural, emotional, psychological, mental health, social and vocational consequences (Ralph and Derbyshire, 2013; Radford *et al.,* 2013; Willmott *et al.,* 2014). The consequences of a brain injury have

been well researched, and have established that the impairments most likely to negatively affect return to work are the following psychosocial consequences: depression, impaired insight, executive dysfunction, anxiety, mental health problems and reduced motivation (Hewitt *et al.,* 2006; Williams *et al.,* 2010; Ashley *et al.,* 2012; Radford *et al.,* 2013). In addition, cognitive deficits such as a poor memory and a lack of ability to generalise have also been reported as common consequences (Kreutzer *et al.,* 2003; Ghajar and Ivry, 2008; Schmitter-Edgecombe and Seelye, 2012). Surprisingly motor problems appear to cause least difficulty although dizziness, sleep problems and fatigue have been reported to impact some, in addition to communication problems and pre morbid substance abusive lifestyles (Harradine *et al.,* 2004; Englander *et al.,* 2010; Schnieders *et al.,* 2012). Interestingly other than vocational consequences there is little mention of wider occupational consequences within the literature. Brain injury usually results in different combinations and severity of physical, cognitive and behavioural difficulties often within a working age population; therefore it has huge health, social and economic impacts.

2.2.4 Work

Within this research the following definitions of work and employment have been used. Work is defined as an "activity involving mental or physical effort done in order to achieve a result" and "the activity or job that a person does to earn money" (Waite, 2013, p.1072). Employment is defined as "the state of having paid work" or "a person's work or profession" (Waite, 2013, p.293). I decided to research return to paid work rather than unpaid work or volunteering as throughout my professional experience most people I have worked with following brain injuries have sought to return to paid work, and only accepted unpaid work or volunteering as a way of attaining paid work.

It is generally accepted that engaging in paid work can be good for physical and mental health and well-being, provides an independent financial income, structures the day, and provides social contact and a sense of purposefulness (Johnsson and Andersson, 1999; Winefield *et al.,* 2002; Waddell and Burton, 2006; Barnes and Holmes, 2007). When young adults gain employment it can "represent entry into a mature, adult world of responsibility and respect" (Winefield *et al.,* 2002, p.4). Work can define aspects of status, social engagement, societal expectation and identity, yet for most individuals following a brain injury return to paid work can be impossible (Yerxa, 1998). Variation appears to

exist in the rates of individuals following a brain injury returning to paid work, although these varied research findings could be due to differences in injury severity within participant samples and a lack of uniform criteria defining return to work (Ben-Yishay *et al.,* 1987).

There is however evidence that the workplace can also cause ill health, especially in relation to stress, musculoskeletal disorders and psychosocial features (Department for Work and Pensions and the Department of Health and the Health and Safety Executive, 2005; Waddell and Burton, 2006). For example work related stress, depression and anxiety amongst National Health Service (NHS) staff in the United Kingdom results in an estimated cost of £700 million a year (Mashta, 2009). Research has also established that conflict at work can lead to depressive symptoms, and that job satisfaction is strongly associated with depression and anxiety (Faragher *et al.,* 2005; Meier *et al.*, 2014). On considering engagement in work over a longer term and completing an extensive study with 174, 438 participants over 10 years, Cooper (2013) found that job insecurity increases the risk of coronary heart disease, so it appears there can also be a negative side to work.

The beneficial effects of work however do appear to outweigh the risks. Work can also be therapeutic with people coming off benefits and re-entering work, reporting "improvements in income, socio-economic status, mental and general health and well-being" (Waddell and Burton, 2006, p.3). The Office for National Statistics Well-being Programme has also shown that the amount and quality of social connections with people around us are vitally important to our well-being and indeed work provides the opportunity to access these (Randall, 2015).

Johansson and Tham (2006) described characteristics of the meaning of work for individuals following an acquired brain injury in Sweden, although it has to be noted that five of their 10 participants had sustained a cerebrovascular accident/stroke, so this may have influenced their results. They established that their participants considered returning to work a personal success, but that they experienced work as a more important social activity following their injury than a primary activity in their life (Johansson and Tham, 2006). This suggests that the meaning of work may change for individuals following their brain injury.

2.2.5 Predicting return to work following a brain injury

Currently it is not feasible to predict successful return to paid work for individuals following a brain injury. It has however been established that at one year post injury follow up, individuals with higher performance intelligence quotient and verbal memory scores are more likely to return. Injury severity, occupation, education, gender, marital status and hospital length of stay have all been suggested as potentially influencing return to work, and for individuals with managerial or professional prior employment they are considered three times more likely to return to work than manual labourers (Walker *et al.,* 2006). Esbjornsson *et al.* (2013) assessed cognition during the 12 months following a traumatic brain injury for 16 individuals in Sweden, and found that their four participants who returned to work were less cognitively impaired than those that didn't return. Interestingly in Finland, Saltychev *et al.* (2013) carried out a systematic review evaluating evidence on pre and post injury predictors of vocational outcome after traumatic brain injury. Their research found weak evidence that age, educational level, severity of traumatic brain injury, level of depression and anxiety and gender may be predictive of vocational outcome, but also claimed that there is no strong evidence that vocational outcomes after traumatic brain injury can be predicted (Saltychev *et al.,* 2013).

In contrast to the findings of Saltychev *et al.* (2013), following psychological testing of individuals with severe brain injuries, Ryan *et al.* (1992) predicted return to work with 77% accuracy, establishing barriers such as reading comprehension, verbal memory, dysphasia and depression. Also Van Velzen *et al.* (2009b) carried out a systematic review in the Netherlands, looking at the prognostic and non-prognostic factors of return to work in people following acquired brain injury. Strong evidence was found by them that both injury severity (Glasgow coma scale) and suffering from depression or anxiety were not associated with return to work, so predicting successful return to work following a brain injury continues to be difficult.

An increase in the self-awareness of an individual following a brain injury has been associated with improved employment status, although this relationship is unclear, and to improve understanding of this could have implications for the development of more effective rehabilitation (Strong, 2006). Shames *et al.* (2007), following a literature review in Italy, also proposed that following traumatic brain injury, self-awareness and motivation are necessary for successful rehabilitation, but also that accurate prediction of

whether these individuals can successfully return to work is currently not feasible. Landa-Gonzalez's (2001) research showed that training using processing strategies such as self-prediction and the use of notepads facilitated improved awareness and work functioning sometimes many years after injury. However, it is currently unknown if these changes help return to paid work.

2.3 The context in the United Kingdom

This second section of part one introduces the context in the United Kingdom in relation to the research. Relevant Government frameworks and guidelines and additional factors such as the Independent Review of Sickness Absence and the Government's Response, the Department for Work and Pensions, the Disability and Health Employment Strategy and state welfare benefits are critically reviewed.

2.3.1 United Kingdom Government frameworks and guidelines

In 1997 the Department for Work and Pensions was established. Since then the Department for Work and Pensions has led a political drive to improve work retention, with its current broad message being that work is good for individuals' health (Ross, 2007). The Government Department of Health introduced two relevant National Service Frameworks: the National Service Framework for long-term conditions in 2005 and the National Service Framework to improve mental health and wellbeing in 2012 (DH, 2005; 2012). The National Institute for Health and Care Excellence (NICE) also introduced head injury quality standards, relevant to brain injury and return to paid work (NICE, 2014). It is unclear however how both of these National Service Frameworks and the National Institute for Health and Care Excellence head injury quality standards have practically impacted individuals' return to paid work following a brain injury, employers or the workplace (DH, 2005; 2012; NICE, 2014).

2.3.1.1 The National Service Framework for long-term conditions

This National Service Framework set out 11 quality requirements, based on available evidence at that time, to change the way health and social care services could support people with long term neurological conditions (DH, 2005). Generally this Framework aimed to provide service users with more choice, improved and more individual assessment, and support for them to live independently and as part of society. Of particular relevance are two of its quality requirements. Quality requirement four which

states that people with long term neurological conditions are to receive the help they need "for ongoing community rehabilitation and support", and quality requirement six which states "to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable to find, regain or remain in work" (DH, 2005, p.4). This Framework suggests how local rehabilitation services may achieve these requirements, such as better working between health care professionals, Department for Work and Pensions staff and the provision of more vocational rehabilitation services designed to meet the needs of people with long term conditions. The Framework however acknowledges that currently there is a large shortfall. Whilst helpful, it is unclear if this Framework has achieved its aims, if its implementation has been successful, if it is being measured, and indeed if it has had any impact on individuals' return to paid work following a brain injury or their employers.

2.3.1.2 The National Service Framework to improve mental health and wellbeing

This Framework is relevant as individuals following a brain injury often go on to develop mental health difficulties. This Framework set out advice regarding how local organisations could improve mental health outcomes in their areas (DH, 2012). Most relevantly stressing that fewer people should "experience stigma and discrimination and that services should work together to support people with mental health problems to maintain, or return to, employment" (DH, 2012, p.8). The Framework advocates better training for frontline staff in relation to mental health and the principles of recovery. It also advocates individuals having better access to Jobcentre Plus Disability Employment Advisers and referral to specialist work programmes such as Access to Work (which provides grants to pay for practical work support), Work Choice (which helps to get and keep a job), and residential training. Again however, the impact and success of this Framework doesn't appear to be being measured to demonstrate if it has any impact on individuals' return to paid work following a brain injury or their workplace environments.

2.3.1.3 The National Institute for Health and Care Excellence head injury quality standards

These quality standards were established in 2014 (NICE, 2014). The standards set time limits for individuals following a traumatic brain injury, stating that they must receive specific assessment if their symptoms persist for more than 72 hours post injury. The most relevant standard to this research however is quality standard seven, which is for community rehabilitation services for people aged 16 and over following traumatic brain

injury. Quality standard seven claims that community-based neuro-rehabilitation services should provide a range of interventions to help support people with "continuing cognitive, communicative, emotional, behavioural or physical difficulties", and specifically states to "regain independence and return to their normal daily lives for example, going back to work" (NICE, 2014, p.32). This standard states that from 2014 community-based neuro-rehabilitation services should be available to help individuals return to work following a brain injury. These standards are welcomed by the brain injury community, but it is unclear to all how they are being implemented, and how their impact and success are being measured.

2.3.2 The Independent Review of Sickness Absence and the Government Response

On recognising the scale of sickness absence in the United Kingdom in 2011, the Government asked Dame Carol Black, National Director for Health and Work and David Frost, Director General for the British Chambers of Commerce, to assess sickness absence (Black and Frost, 2011). An Independent Review took place and included rigorous examination and a review of the roles that healthcare professionals, employers and Government services played (Black and Frost, 2011).The Review concluded that each year 140 million working days were lost to sickness absence and although most ended in a return to work, over 300,000 people became out of work and went onto health-related state benefits (Black and Frost, 2011). The Review acknowledged weaknesses in the United Kingdom system, and recommendations were made not only to improve effectiveness but also to help individuals return to paid work. Specific changes were recommended to improve sickness certification to collect more informative data. The Review also made transparent that employer management of long-term absence from work hugely varied and that less well paid, less qualified employees and those working in smaller organisations were more likely to be excluded from back to work interventions and were more likely to access state benefits.

In response to this Review, the Government published Fitness for Work, the Government Response (DWP, 2013). The Government spends £13 billion a year on health-related benefits and its response aimed to reduce sickness absence and introduce ways of supporting individuals with health conditions to both stay in and return to work. Response recommendations included: General Practitioners having further training on the use of Fit notes, welfare reforms with the new Universal Credit replacing income-

based Employment and Support Allowance and providing employers with tax relief on health related interventions worth up to £500 per employee. Fit notes had been previously introduced in 2010 and are for General Practitioners to provide evidence of advice given about fitness for work. Most interestingly however, this response included seven success indicators to measure its success, including measuring professional knowledge and perceptions of the importance of work to health and health to work, reducing the number of people out of work due to ill-health and provision of case management for employees with complex needs requiring ongoing support to enable return to paid work (DWP, 2013).

These recommendations could favourably impact individuals' return to paid work following a brain injury. As a follow up to the Fit note, Allied Health Professions Advisory Fitness for Work Reports was piloted in 2012 by the Chartered Society of Physiotherapy (Chartered Society of Physiotherapy, 2012). The intention was that General Practitioners would use these new reports (following consent of the individual involved), written by occupational therapists, physiotherapists or podiatrists to help them to complete Fit notes, and to better advise employees and employers about return to work, but to date little has been published about their impact and success.

2.3.3 The Disability and Health Employment Strategy

The Department for Work and Pensions published the Disability and Health Employment Strategy in 2014 whilst announcing that there were 259,000 more disabled people in employment than the previous year and over 3 million in total (DWP, 2014a). Unfortunately it is not possible to identify how many of these individuals had sustained a brain injury. What is of most interest is that the Department for Work and Pensions stated that for 2015/16 there will be an overall budget of £350 million for Disability and Health Employment support, and that by January 2017 all buses will be accessible to disabled individuals. This is relevant as some individuals are unable to drive post injury and may rely on public transport. This means that it is important that individuals following a brain injury are advised to access this support through Department for Work and Pensions services such as Work Choice, Access to Work, Employment and Support Allowance, which provides financial support if unable to work or the Work Programme which supports work experience and training for up to two years, but yet again there is

little evidence of communication or collaboration with employers regarding their needs (DWP, 2014a).

2.3.4 State welfare benefits

Headway, the United Kingdom charity that supports individuals following a brain injury, suggests that individuals and their families seek professional advice about state welfare benefits as the system is so complex (Headway, 2014). It is likely that following a brain injury individuals will be able to apply for and claim: Disability Living Allowance (a tax-free benefit to help with extra costs due to disability), Personal Independence Payments (currently being phased in to replace Disability Living Allowance for those aged 16–64 years), Employment and Support Allowance for those who have difficulty working and Jobseekers allowance to help whilst looking for work. These applications are currently under review in relation to the new Universal Credit system, but are generally complicated to complete, although it is anticipated that Personal Independence Payments will totally replace Disability Living Allowance for all applicants by 2017 so will hopefully be less complex.

2.4 Exploration of the occupational therapy perspective on health and relevance of occupational theory

This third section of part one explores the occupational therapy perspective on health and the potential relevance of occupational theory to the research. This is important to review as it will help put the occupation of paid work within the research into perspective. This section explores the occupational therapy perspective in relation to the research and briefly reviews the relevant underpinning history and theory of occupational therapy, occupational science, the definition of occupation and links between occupation and health.

2.4.1 The underpinning history and theory of occupational therapy

Occupational therapy began at the turn of the 20th century and since then its central purpose has been to use occupation as its core concept and as a means of intervention (Evans, 1987; Barris *et al.,* 1988; Hocking, 2008a). Occupational therapists believe that participation in occupation influences individuals' minds and bodies, that purposeful and meaningful activity has health benefits, and that a lack of occupation can result in poor health (Wilcock, 2001a). Occupational therapy is therefore underpinned by the belief

that, in order to survive, individuals have a basic need and drive to be occupied (Wilcock, 2007; Tabor Connor *et al.,* 2014).

Hocking (2008a), on review of the practice and historical accounts of pioneering occupational therapists within the United Kingdom, observed evidence of their belief in the "transformative power of crafts" that they used with patients (Hocking, 2008a, p.146). These pioneering therapists believed that people expressed themselves through the things that they did, despite a lack of research evidence at that time. In the 1930s occupational therapy's philosophical roots included both mixed Romantic and Rational perspectives (Hocking, 2008c). Romanticism believed that people's inspiration came from their experience and emotion and Rationalism required actions to be based on facts and "rigorous inquiry" (Hocking, 2008b, p.185). Reflecting its roots in Romanticism, occupational therapy, in its early years, used crafts as occupations to produce goods that provided an income for in patients and that supported their discharge skills (Pierce, 2014). Due to a combination of advancements in medicine, science and changes in society at the time this approach became less of a focus for occupational therapy. The belief that individuals needed occupation to maintain their health however was retained as its main focus (Barris *et al.,* 1988; Whalley Hammell, 2009). Romantic and Rational philosophies clashed and following the Second World War, Rationalism dominated, as science became more valued (Hocking, 2008c). This saw a decline in Romanticism and the emergence of more Rational and biomechanical approaches within occupational therapy (Hocking, 2008c). Due to these factors a more medical model approach was adopted and the use of occupation as a therapy for psychosocial problems waned. Occupational therapy needed to develop its knowledge base, to be part of a more Rational world than Romantic one and to be accepted (Hocking, 2008b). Given the psychosocial difficulties faced by many individuals following a brain injury, this decline in Romanticism and increased medical model approach must have impacted the occupational therapy interventions this client group engaged in.

A need was later identified for a return to the occupational roots of the occupational therapy profession (Kielhofner, 1992). Mary Reilly's (1962) occupational behaviour theory guided this development of occupational therapy and her students Gary Kielhofner and Janice Burke (1980) both described occupational therapy's historical knowledge base

crisis as a paradigm shift away from the biomechanical approach used in the days of the medical model and towards a more holistic, occupation focused paradigm (Pierce, 2014).

It was recognised that the medical model was unable to meet the complex needs of many disabled individuals. It was also recognised that a lack of occupation resulted in poor health, and that occupation could be used to promote health (Kielhofner, 1992). Indeed this could be very relevant to the brain injury population and return to paid work rehabilitation. Following this, Kielhofner (1997) proposed that a new occupational therapy paradigm had emerged which had three core assumptions; that humans had an occupational nature, and that an individual could experience occupational dysfunction, and that occupation could be used as a therapeutic medium. This strongly resonated with Romanticism. This highlighted the advancement of occupation as a therapeutic measure and the study of the effect of occupation upon humans (Wilcock, 2001b). This refreshed interest in occupation opened a revived Romantic approach to understanding humans as occupational beings and their experiences of occupation. Occupational therapy further evolved with the emergence of occupational science in 1989. Occupational science was created out of occupational therapy to produce knowledge needed by practice and has provided many benefits to occupational therapy, and could provide knowledge required to improve return to paid work following a brain injury (Clark *et al.,* 1991; Molineux, 2004; Pierce, 2014).

2.4.2 Occupational science

Occupational science is the study of humans as occupational beings, and is a new science which is continuing to establish a knowledge base and to refresh the identity of occupational therapy (Yerxa *et al.,* 1989; Wilcock, 1991; Clark *et al.,* 1991). Occupational science was "conceived at the University of Southern California through the vision of Elizabeth J. Yerxa" and named by her (Clark, 1997, p.86; Wilcock, 2001b). The first paper published defined occupational science as "the study of the human as an occupational being including the need for and capacity to engage in and orchestrate daily occupations in the environment over the lifespan" (Yerxa *et al.,* 1989, p.6). Occupational science is a basic science seeking to "forge new understandings of the meanings in people's lives", to provide a knowledge base which provides evidence in relation to what people do and how this influences their health, and to develop a body of knowledge about occupation to

enable occupational therapists to further expand an occupational perspective in their practice (Hocking, 2000a; Turner, 2007, p.11; Rudman *et al.,* 2008).

2.4.3 The definition of occupation

The College of Occupational Therapist's (2015b) definition of occupation in the United Kingdom was provided in Chapter 1, 1.6. The World Federation of Occupational Therapists (WFOT, 2015b, p.1) states that occupations refer to the "everyday activities that people do as individuals, in families and with communities to occupy their time and bring meaning and purpose to their life". Occupations include things that people need to, want to and are expected to do. An occupation is believed to have a pace, a beginning, an end, can be shared or carried out individually and has a cultural meaning to individuals (Pierce, 2014). It is not always possible for individuals to have a choice, control or the opportunity to engage in the occupations that they choose to, so it is unrealistic to assume that there is always a positive relationship between occupation, well-being, and health (Whalley Hammell, 2009; 2014).

2.4.4 Links between occupation and health

One of society's greatest challenges is to understand the relationship between occupation and health. The most quoted occupational therapy belief key to the relationship between occupation and health is that of Mary Reilly (1962, p.2) who stated that "man, through the use of his hands as they are energised by mind and will, can influence the state of his own health". Wilcock (1998, p.340) claimed that humans have "occupational needs" which are related to health, and that they use occupations to survive and to overcome physiological, psychological or social discomfort. Research provides moderate to strong support for the belief that occupation influences health and well-being, but currently the occupational needs of individuals' following a brain injury returning to paid work are not known (Hocking, 2000a). Wilcock (2007, p.5) believes that occupations which are perceived as "doing, being, becoming and belonging are essential to survival and health".

Clark and colleagues in 1993 carried out a three year randomised clinical trial, referred to as the Well Elderly Study, at the University of Southern California (Clark *et al.,* 2004). This study included 361 well elderly, ethnically diverse individuals and its main research theme was health through occupation. This trial design randomly allocated participants to one of three groups for a nine month period: a group programme based on occupational therapy

lifestyle redesign, a control group involving participation in non-professionally led activities and a group that provided no treatment. Two thirds of the 361 participants had nine months of intervention. The occupational therapy group outcome benefits included physical, social and mental health functioning and provided evidence that the lifestyle redesign group not only produced financially effective results, but that most of the participants "were unaware of the relationship of occupation to health and tended not to think about how their choices affected their physical and mental health as well as longevity and quality of life" (Clark *et al.,* 2004, p.200). This study demonstrated that preventive occupations promoted health, and explained the relationship between health and occupation in terms of a healthy balance of occupations (Yerxa *et al.,* 1989; Clark, 1997; Clark *et al.,* 2004).

Currently little is known about if and how returning to paid work following a brain injury impacts individuals' health and wellbeing and the reasons that these individuals choose to return following their injury. As less financial resources become available in longer term health and social care, and due to medical and technological advances individuals following a brain injury are surviving more severe injuries and living longer. It is therefore crucial that research is carried out to be able to offer these individuals more choices for their future.

2.5 Review of the current occupational therapy context in the United Kingdom

This fourth and final section of part one briefly explores the occupational therapy context, strategy and guidance from the College of Occupational Therapists, the professional body of occupational therapists in the United Kingdom.

The College of Occupational Therapists, in 2008, published a vocational rehabilitation strategy which stressed the importance and significance that occupation and employment have on a person's health and wellbeing (COT, 2008). This strategy however stressed this main occupational therapy provision as being functional and capacity assessment, task analysis and modification orientated rather than occupationally focussed. This, whilst helpful, reflects the historical decline in Romanticism and dominance of the Rational approach as previously explained by Hocking (2008c).

The College of Occupational Therapists next published a brief guide to current occupational therapy vocational rehabilitation practice in the United Kingdom, and

stated that “the majority of occupational therapists have little or no experience of applying their occupational therapy skills to work-related issues, or of becoming involved in workplace rehabilitation” (COT, 2009, p.1). Whilst this concerns me, given the occupational roots of the profession, it is not surprising and may still reflect the longer term aftermath of the professional decline in Romanticism and dominance of Rationalism (Hocking, 2008c). It is helpful however in acknowledging that the profession has developmental needs in relation to the vocational rehabilitation needs of service users, but further reinforces the need for this research.

More detailed guidance was published in 2013 within the Acquired Brain Injury Guide for occupational therapists (COT, 2013). This guidance utilised the National Service Framework for long term conditions to provide joined up guidance, however it is focused on acute service delivery and does not address the longer term needs of these people. Despite this, it does acknowledge and instruct occupational therapists to consider individuals’ “vocational needs and to refer to a specialist vocational rehabilitation programme”, although does not identify how or where these services are, nor how effective (COT, 2013, p.43). This is a positive step to providing vocational rehabilitation services to individuals following a brain injury. A more research evidence based approach is needed however to not only provide guidance, but to support and in particular guide and help, the application of evidence based guidelines to help occupational therapists integrate best evidence into their vocational rehabilitation practice, and to audit its effectiveness (Hammond *et al.,* 2005; Taylor, 2007; Blackwood and Wilson, 2009).

2.6 Part one summary

Part one has established a need for research evidence to help better understand the barriers and success factors of returning to paid work following a brain injury. This evidence would address the financial, health and social impacts that have been highlighted of individuals following a brain injury.

Although engaging in paid work can be good for health and well-being, given certain circumstances work may impact negatively on health (Faragher *et al.,* 2005; Waddell and Burton, 2006; Barnes and Holmes, 2007; Cooper, 2013; Meier *et al.*, 2014). The beneficial effects of work appear to outweigh risks especially when re-entering work, however the meaning of work may change for individuals following their brain injury (Johansson and

Tham, 2006). Furthermore, it is not always possible for individuals to control or have the opportunity to engage in the meaningful occupation of work that they choose, so there may not always be a positive relationship between work, well-being and health (Waddell and Burton, 2006; Whalley Hammell, 2009; 2014). Currently little is known about the occupational needs and if and how returning to paid work following a brain injury impacts individuals' health and wellbeing (Hocking, 2000a). Exploring the occupational perspective on health and occupational theory to the research could lead to an increased understanding of any relationship between return to paid work and health following a brain injury.

The National Service Frameworks for long-term conditions and to improve mental health and wellbeing and the NICE head injury quality standards may potentially have impacted individuals' return to paid work following a brain injury, but there is no outcome data regarding impact on individuals' return to paid work or their employers, or how impact is currently being measured (DH, 2005; 2012; NICE, 2014). The Department for Work and Pensions are attempting to help disabled people to return and remain in employment. This help however does not appear to have included collaboration with employers. Outcome measures of success are needed other than purely the number of disabled people that return to work (DWP, 2014a).

It has been highlighted that it is incredibly difficult following a brain injury to return to paid work due to resulting psychosocial, cognitive and/or physical deficits (Vandiver *et al.,* 2003; Schonbrun *et al.,* 2007). Considering their psychosocial difficulties, the decline in Romanticism and increased use of the medical model approach, the content and effectiveness of their vocational rehabilitation warrants attention (Hocking, 2008b). Occupational therapy has developmental needs in relation to vocational rehabilitation and the needs of individuals following a brain injury, which this research could inform (Hocking, 2008c). Evidence is needed to establish researched based guidelines to guide future, effective vocational rehabilitation interventions. Support and guidance is also needed to help therapists apply evidence based guidelines, and to integrate them into their practice. A better understanding of how individuals following a brain injury and their employers currently experience return to paid work is needed if future rehabilitation services and return to paid work success are to be improved.

As less financial resources become available in longer term health and social care, and due to medical and technological advances individuals following a brain injury are surviving more severe injuries and living longer, it is therefore crucial that research is carried out to offer these individuals more choice for their future.

Part two

This second part of chapter two provides a review of the literature and critically synthesises and establishes a baseline of the existing knowledge and evidence base in relation to the research keywords. This part of chapter two initially introduces the methods I used to establish the literature that was reviewed. It then goes on to critically synthesise the appraised literature in relation to the factors that impact the return to paid work of individuals following a brain injury.

2.7 Introduction to the literature review

The methods I used to search for, manage, analyse and establish the literature reviewed were informed by both Hart (2005) and Aveyard (2014), and are explained below and with the use of six Appendices to provide evidence of methodological rigour. The keywords and thesaurus terms used to carry out the literature search, the inclusion, exclusion, search strategy criteria and the University databases searched are presented separately and respectively across Appendices one to three. A final core yield of 44 research articles was established for inclusion in this review following application of the inclusion and exclusion criteria, hand searched articles being added, and addition of Zetoc alert articles highly relevant to the research. A summary of the literature search history and yield by database is presented in Appendix four. Following critical appraisal of each individual article and my developed appreciation of their similarities and differences, it was possible to code each article and to see five thematic patterns develop which are explored below (Aveyard, 2014). By using this coding, appropriate articles were grouped together within the same code and a comparative analysis carried out (Aveyard, 2014). Appendix five provides a breakdown of each individual article, and evidence of how each was coded to extract the five themes from the yield review literature. Appendix six presents an overview and map of the five themes I critically appraised and that are discussed in relation to the research aim. Of the 44 yield articles only five are from the United Kingdom and 39 from outside of the United Kingdom. Appendix six also shows that several of the articles are relevant to more than one of the themes, and also illustrates sub themes within most of the themes. The five themes to emerge from the yield literature I reviewed and for critical synthesis and discussion are: global return to work rates; factors impacting and predicting return to work; factors relevant to sustaining

work; the meaning of work, quality of life and life satisfaction; and self-awareness and adaptation.

2.8 The five review themes

2.8.1 Global return to work rates

Despite background and previously presented literature citing one third, evidence suggests that global return to paid work rates following a brain injury range from between 32-60% of injured survivors (Walker *et al.,* 2006; Holtslag *et al.,* 2007). In the USA there is between a 32-56% return to paid work rate, and within Europe a 40-60% reported return rate (Walker *et al.,* 2006; Bjorkdahl, 2010). These two ranges are not significantly different, so it appears that return to work following a brain injury is an international issue and not just isolated to the United Kingdom. Only one study from the United Kingdom was sourced that researched the return to paid work rate of 90 individuals following moderate to severe traumatic brain injuries (Friedland and Potts, 2014). Friedland and Potts (2014), whilst consistent with the global return to paid work rate general outcome literature reviewed, reported that 40% of their sample had returned to work at one year post injury, but unfortunately they did not research whether these individuals remained in work, nor review the retrospective records and reasons why the remaining 60% had not returned.

In the USA, Shigaki *et al.* (2009) at two years post traumatic brain injury, using a non-experimental longitudinal survey, determined the outcomes for 49 individuals in terms of their employment status, income and help required. They not only found higher levels of employment and earned income than previously reported for one year post injury in the USA, but noted that this declined and that the costs of brain injury remain high for injured individuals, their families and society as injured individuals move through the stages of recovery. From this study, although relatively small, it appears that despite returning to work within the first year following an injury, that there is no guarantee that employment is sustained. As these results are based on the sample self-reporting and from the USA they are difficult to generalise to the United Kingdom.

Bjorkdahl (2010) reported a different outcome when exploring being able to predict return to work in Sweden following a traumatic brain injury. Bjorkdahl (2010), following annual interviews with 65 individuals (39 men and 26 women) from one to five years post

injury, claimed that before their injury 77% of them were employed or studied, and that after their injury 80% had no occupation. After five years however 40% of them had returned to work. This is a different picture to the studies above, as although final findings are consistent with the general outcome literature, these results are at five years post injury, and all of their participants had received vocational rehabilitation. Again however this is difficult to generalise, as only 44.6% of the participants had a traumatic brain injury and the remainder had experienced sub arachnoid haemorrhage, encephalitis, anoxia or the consequences of treatment or resection of a brain tumour. Sweden, however, has a social insurance system which provides sickness benefit for those prevented from working by disease or injury which is time limited then assessed, and if return to work is considered not possible individuals are provided with a pension. Although the rate of return to work appears consistent with the United Kingdom, a comparison of the lived experience recovery journey of the injured individuals from each country would be interesting due to the four year time difference and the similar final outcome.

Two studies reported that driving independence may impact return to work rates. In the USA, Kreutzer *et al.* (2003) used multi centre analysis to examine the job stability variables of 186 individuals following traumatic brain injuries at one to four year annual follow ups. Their participants had experienced 61% severe, 22% moderate and 17% mild injuries. Thirty five percent of them were employed at one year, 37% at two years and 42% at three or four years. Quite different to Bjorkdahl (2010), Kreutzer *et al.* (2003) concluded that if individuals following a traumatic brain injury were not working at one year post injury that they were more likely to be unemployed at two or three years, but more interestingly they found that driving independence highly influenced and was significantly related to employment stability. It is hard to generalise these culturally divergent findings, but it could be that driving independence is a pragmatic issue following injury and relevant to return to paid work in the United Kingdom. Again consistent with the global return to paid work rate general outcome literature, Forslund *et al.* (2013) in Norway, reported the return to paid work rate following traumatic brain injury at two year follow up to be 44%. In their prospective cohort of 100 individuals who had experienced moderate to severe injuries (aged 16 to 55 years), they described employment outcomes and assessed the impact of personal and environmental factors

on employment outcome. The environmental factors reported as having a positive impact were the support of friends, rehabilitation services, well-coordinated healthcare and individuals having their own transport. It is generally acknowledged that Scandinavian countries provide better healthcare insurance against disability, sickness and unemployment than the United Kingdom, so this study is difficult to generalise. However the return to paid work rate is consistent with the United Kingdom, and furthermore a potential relationship between individuals having their own transport and successful return to work has been identified and could be relevant.

It is not clear if rehabilitation following a brain injury impacts return to work rates. In the USA Walker *et al.* (2006) used a prospective collaborative cohort study to evaluate return to paid work after traumatic brain injury with 1341 individuals. Their participants had moderate to severe injuries and were aged 18 to 62 years. They found that the type of occupation influenced return to work, and that the rate of successful return was found greatest for professional and managerial occupations (56%), was lower for skilled occupations (40%), and was lowest for manual labour at (32%), and at one year post injury 39% of the participants were in either full or part time employment. Their findings, whilst consistent with Friedland and Potts's (2014) United Kingdom outcome rate, differ in that the participants in the Walker *et al.* (2006) study had received in patient interdisciplinary rehabilitation, so the benefits of their rehabilitation need to be questioned. Although the findings of Walker *et al.* (2006) are difficult to apply to the United Kingdom as they are culturally diverse, they do raise the question of the benefits of return to work rehabilitation, and how it impacts return to work success.

Higher return to work outcome rates has been reported by three studies across the Netherlands and in Finland. Within the Netherlands, Holtslag *et al.* (2007) quantified the prevalence of return to work after major trauma. Following multivariate logistic regression analysis of the demographic data of 214 individuals following trauma (184 men and 30 women), who were full time employed at the time of their injury, they reported that around 60% of the participants returned to their pre-injury work status after their major trauma. Whilst this is a higher outcome rate than the United Kingdom, it has to be noted that the participants were a large unselected group of consecutive severely injured patients including some who had also had a spinal cord injury, so the study is not generalizable. Also in the Netherlands, Benedictus *et al.* (2010) carried out a longitudinal

cohort study with 434 individuals following traumatic brain injury of various severities, and concluded that half of their participants were able to resume their previous vocational activities, but again this is not generalizable to the United Kingdom as their study lacks detail of the specific injury severities. In Finland, Waljas *et al.* (2014) reported an exceptionally high return to work rate of 97.2% for their 109 participants, however these individuals had all sustained mild traumatic brain injuries and no follow up data in relation to job retention was provided, so this evidence is not easily generalizable to the United Kingdom.

Concern regarding return to paid work rates following a brain injury is not isolated to the United Kingdom and appears to be an international issue with high costs for injured individuals and society (Shigaki *et al.,* 2009). Only one United Kingdom study reported a 40% return to paid work rate, however this is consistent with global general outcome literature reviewed (Friedland and Potts, 2014). Despite similar outcomes in relation to return to paid work rates, the recovery journey of individuals following a brain injury vary in relation to the time it takes to return to work and the rehabilitation provided. In Sweden, Bjorkdahl (2010) reported similar return rate outcomes to the United Kingdom, but reported five years post injury rather than one and where all of their participants had received vocational rehabilitation. It is not clear if rehabilitation following an injury impacts return to work rates. The findings of Walker *et al.* (2006) are difficult to apply to the United Kingdom as they are culturally different. However, they do question the benefits of return to work rehabilitation and how it impacts return success. Their rate of return to work is consistent with the United Kingdom, but all of their 1341 participants had received in patient interdisciplinary rehabilitation where the 90 United Kingdom participants had received minimal intervention (Friedland and Potts, 2014). Driving independence and an individual having their own transport post injury could impact return to work rates, but it is currently unclear if this is relevant in the United Kingdom (Kreutzer *et al.,* 2003; Bjorkdahl, 2010).

2.8.2 Factors impacting and predicting return to work

This theme contains significantly more research literature from the yield than the other themes. It explores the most established ongoing symptomatic factors to impact return to paid work, and then reviews the unemployment risks and how currently return to paid work is predicted.

2.8.2.1 Ongoing symptomatic factors

The researched ongoing factors to impact return to work after a brain injury reviewed below are: fatigue, cognitive and behavioural difficulties, anxiety, depression, psychiatric symptoms, emotional dysregulation and communication difficulties.

Four studies, including two from the United Kingdom, highlight fatigue as an impacting factor during return to work. All four of these studies have small samples, are predominately qualitative, triangulate and establish fatigue as an ongoing issue. In the United Kingdom Hooson *et al.* (2013), on exploring return to work with 10 participants following traumatic brain injuries, identified that excessive fatigue generated a fear of failure for them. Of their 10 participants eight were men; therefore this may have influenced the findings as women may have had different experiences. Also in the United Kingdom, McCrimmon and Oddy (2006) investigated the role of cognitive functioning, fatigue, mood and behaviour in return to paid work following moderate to severe traumatic brain injury. They established that 13 of their participants who remained unemployed reported significantly higher levels of fatigue and depression compared to their 20 participants who were able to return to work. Their research suggests that fatigue not only impedes ability to return to work following a brain injury, but that further research is required in relation to why it can be accentuated by fear, noise and stress. These findings are supported by Rubenson *et al.* (2007) and Van Velzen *et al.* (2011). In the Netherlands, Van Velzen *et al.* (2011) established tiredness as the most limiting factor related to return to work for their 12 participants (nine men and three women) who had experienced moderate to severe acquired brain injuries. Similarly in Sweden, Rubenson *et al.* (2007) when they explored the experiences of return to work of eight participants following acquired brain injuries, reported fatigue to be a barrier, and concurring with McCrimmon and Oddy (2006) also found fatigue to be accentuated by strong sounds.

Three larger, mixed method studies and one single case study reported cognitive problems as impacting return to work, in particular difficulties remembering and concentrating. In Sweden, Bjorkdahl (2010) followed up 65 individuals following traumatic brain injury and explored return to work. The most frequent problems their participants reported were: remembering (96%), concentrating (91%) and getting things done on time (86%). Similarly in the USA, Artman and McMahon (2013) researched the self-reported functional limitations of 160 individuals following traumatic brain injury in relation to job

maintenance following return to work, and found that memory loss, attention, concentration and behavioural difficulties were the most reported. Despite Artman and McMahon (2013) relying on the self-report and editing of their participants who may have lacked self-awareness, their findings are reinforced with consistent findings in the Netherlands by Benedictus *et al.* (2010). Benedictus *et al.* (2010) also found, when evaluating the cognitive and behavioural disturbances related to return to work for 434 individuals following traumatic brain injury, that their participants encountered problems with cognitive difficulties (62%), behavioural difficulties (55%) and social difficulties (49%). Nimgade and Costello (2003), in the USA, described high levels of frustration being experienced by an individual following a brain injury whilst having to cope with ongoing cognitive difficulties alongside job expectations. Despite this study being only a 64 year old male's single case study, it does support the three previous larger studies. Although none of these studies are from the United Kingdom, clearly it is possible that cognitive difficulties, especially remembering and concentrating may impact return to paid work.

Five predominantly quantitative studies identified anxiety, depression and psychiatric problems as impacting return to work, although again none from the United Kingdom. The smallest of these studies was in the USA and carried out by Power and Hershenson (2003), who investigated the work adjustment of 10 individuals following traumatic brain injury. They established that most of their sample didn't seek vocational rehabilitation until at least one year post injury due to anxiety and depression affecting their self-esteem. Also Franulic *et al.* (2004) in Chile evaluated the psycho-pathological and social situations of return to work for 202 individuals following traumatic brain injury. They established that unemployed participants presented with more severe symptoms of anxiety and depression than those injured participants who were working, although this study did not include detailed information about injury severity, so has limited generalisability (Franulic *et al.,* 2004). Similarly in a larger study, Van der Horn *et al.* (2013) in the Netherlands investigated the relation of the post concussive complaints of anxiety and depression with vocational outcome for 242 individuals with various severities of traumatic brain injury, and found that 67% of the participants had complaints and 22% of them were anxious and 18% depressed. Most interestingly however the frequency of the complaints increased significantly with their injury severity, and reporting of complaints was lower where participants had completely returned to

work (anxiety 9% and depression 5%). With incomplete return to work these scores were 42% and 37% respectively. Considering these study findings, it is possible that anxiety and depression could impact return to paid work in the United Kingdom. This is further reinforced by Dawson *et al.* (2007) who researched return to productivity four years after traumatic brain injury in Canada, and found that scores for participants following traumatic brain injury were significantly different to their control group scores for depression. This study is less generalizable however as it included only 46 participants and presented no uniformity in how productivity was measured. Following research in the Netherlands evaluating employment outcome of 113 individuals following moderate to severe traumatic brain injuries, Grauwmeijer *et al.* (2012) claim that depression and anxiety are the most common problems. They concluded that individuals with these symptoms and impaired cognitive functioning at hospital discharge were at the highest risk of long term unemployment, and that employed participants less often demonstrated these symptoms, were less impaired and had a shorter length of hospital stay (Grauwmeijer *et al.,* 2012). These results need to be generalised with caution as only 94 of the 113 participants completed the study. The findings do however emphasise that anxiety and depression may be limiting factors when returning to paid work following a brain injury.

Only two further ongoing factors, emotional dysregulation and communication difficulties, were reported within the yield literature. Emotional dysregulation was described by Artman and McMahon (2013, p.14) as "behaviour stemming from poor stress tolerance and mood lability". Artman and McMahon (2013) reported that medical symptoms and emotional dysregulation were reliably associated with job maintenance when they researched the self-reported functional limitations of 160 individuals following traumatic brain injury in relation to job maintenance following return to work. Despite emotional dysregulation being highlighted as a factor, this study was reliant on the self-report of participants who may have limited self-awareness, so has limited applicability in addition to a lack of data being included about injury severity. The term emotional dysregulation could also have been potentially confused with the terms stress or depression. Only one study related to communication difficulties on returning to work following a brain injury. Rietdijk *et al.* (2013), in Australia, explored the possible correlation between measures of functional communication skills in the first year after

traumatic brain injury for 14 adults and their later employment using the Functional Assessment of Verbal Reasoning and Executive Strategies. Despite this being a small sample and one participant being lost to follow up, these strategies show promise as a future predictive assessment that could be associated with successful employment outcome, but have no direct applicability to the current research.

Evidence triangulates fatigue as an ongoing issue impacting return to work following a brain injury (McCrimmon and Oddy, 2006; Rubenson *et al.,* 2007; Van Velzen *et al.,* 2011; Hooson *et al.,* 2013). Furthermore, evidence suggests that fatigue may be accentuated by fear, noise, messy environments and stress, but this requires further research (McCrimmon and Oddy, 2006; Rubenson *et al.,* 2007). Although none of the studies originate from the United Kingdom, it is likely that cognitive difficulties, especially remembering and concentrating, could impact return to paid work (Bjorkdahl, 2010; Benedictus *et al.,* 2010; Artman and McMahon, 2013). It is also possible that anxiety and depression may impact return to paid work (Power and Hershenson, 2003; Franulic *et al.,* 2004; Dawson *et al.,* 2007; Grauwmeijer *et al.,* 2012; Van der Horn *et al.,* 2013). The severity, potency and management of these ongoing symptoms however are currently not clear. In addition, the ongoing fatigue reported appears poorly understood especially in relation to the accentuating circumstances.

2.8.2.2 Unemployment risks

Six studies, although none from the United Kingdom, examined unemployment risks following a brain injury. These studies include large sample groups and used either mixed or quantitative methods. Three of these studies are not generalizable as they included predominantly individuals with mild brain injuries (which is less representative within the United Kingdom and relevant to the research), and they were also carried out in the USA, but none the less are relevant and of interest (Doctor *et al.,* 2005; Machamer *et al.,* 2005; Boake *et al.,* 2005).

Doctor *et al.* (2005) examined 418 individuals following traumatic brain injury who had worked pre injury. They established that a greater risk of unemployment existed amongst males aged 25-39 years and for those with more severe injuries. In addition to this study including a mild to severe spectrum of injury severity, it is also difficult to apply to the United Kingdom, as 44 of the participants were lost to follow up at one year. Similarly in

that two thirds of the 165 sample had a complicated mild traumatic brain injury but presenting different findings, Machamer *et al.* (2005), found that participants who failed to maintain stable uninterrupted employment were younger, had lower pre injury earnings and had a pre injury job that did not provide benefits. They concluded that participants' ability to maintain uninterrupted employment was largely related to pre morbid characteristics such as being older, having a higher income before injury, or a pre injury job with benefits. This study does require application caution however as most of the sample had experienced a mild traumatic brain injury. In a further study which explored employment after mild to moderate traumatic brain injury, Boake *et al.* (2005) reported that most of their 210 working age participants remained unemployed at six months post injury, and that the majority of their non-hospitalised participants following mild injury did not work for at least one month, and did not begin working until one to three months after injury. Although of interest, again this is not directly applicable as similar to Doctor *et al.* (2005) and Machamer *et al.* (2005) it mainly researched individuals with predominantly mild injuries only.

Interestingly in relation to risk and age in Chile, Franulic *et al.* (2004) evaluated psycho-pathological and social situations and described the return to work predictors between two and ten years for 202 participants following traumatic brain injury. They found the opposite to Doctor *et al.* (2005), and that factors determining poor return to the workplace was increased age, low educational level, lack of job qualifications and greater cognitive impairment. Unfortunately these results are limited as there was a lack of injury severity detail, but they also conflict leaving it unclear how age may impact unemployment risk especially within the United Kingdom.

Although weak evidence, in France, Fort *et al.* (2011) claimed that pre injury low educational level was associated with difficulty returning to work for medullary or cerebral lesion participants following brain injury when they analysed factors associated with late return to work in 608 road accident victims. It is important to note however that this was only at one year follow up, and that their participants were not only head injured but some had face, neck, thorax, abdomen, spine and lower limb injuries, in addition to 184 of them being lost to follow up, so this study is unfortunately not generalizable.

A more applicable study regarding unemployment risk, although carried out in the USA, is Parks *et al.* (2010). On researching employment rates amongst 3522 traumatic brain injury survivors, Parks *et al.* (2010) concluded that an increasing injury severity was associated with a lower employment rate. They also found that women who were employed full time before a traumatic brain injury were more likely to work part time after their injury than men. It is important to note however that only 51% of this sample group was employed full time before their injury and that this could have influenced the results.

These six studies, despite significant limitations and differences, suggest that potential risks of unemployment following a brain injury could include having a more severe injury, greater cognitive impairment and a lack of job qualifications (Franulic *et al.,* 2004; Parks *et al.,* 2010). Age has been implied as an unemployment risk factor, both amongst males aged 25-39 years and older, however this evidence is conflicting and unclear (Franulic *et al.,* 2004; Doctor *et al.,* 2005).

2.8.2.3 Predicting return to work

There is some overlap between this subtheme in relation to predicting return to work following a brain injury with some studies already presented within the previous sub themes and theme. These studies are referenced only within this subtheme as they have some application to making predictions about return to paid work but I have avoided repetition.

Currently there appears to be no discrete measurement tool available that can accurately predict return to work following a brain injury. Evidence, previously presented however, does suggest some consensus in being able to make limited predictions for return to paid work relating to the presence of fatigue, severity of the injury, an individual's gender, the presence of low mood, behavioural and psychiatric problems and to a lesser degree the ability to drive (Kreutzer *et al.,* 2003; Franulic *et al.,* 2004; Doctor *et al.,* 2005; McCrimmon and Oddy, 2006; Parks *et al.,* 2010; Grauwmeijer *et al.,* 2012; Forslund *et al.,* 2013).

Providing further, although limited, support regarding the presence of fatigue and predicting return to paid work in Finland, Waljas *et al.* (2014), briefly presented in the first review theme, examined the factors relating to return to work following mild traumatic

brain injury for 109 individuals. They found fatigue to be a significant predictor of return to work ($P < .001$), although in their study it was unclear if the participants returned to the same job, a new job or full or part time employment, in addition to all of them having a mild injury and self-reporting, so limiting generalisability.

Four additional, non-United Kingdom, quantitative studies concur with some previously presented study findings in relation to age, injury severity, the presence of depression, presence of mental illness or behavioural disabilities and gender regarding predicting return to work (Hanlon *et al.,* 2005; Corrigan *et al.,* 2007; Schonberger *et al.,* 2011; Bonneterre *et al.,* 2013).

Schonberger *et al.* (2011) in Australia, on exploring functional and employment outcome with 949 individuals following moderate to severe traumatic brain injury, also found increased age and injury severity to be direct predictors of employment outcome. The fact that all participants had received rehabilitation however may have influenced results, in addition to Australians from the age of 55 years having the option of gradual transition to retirement.

In the USA, Hanlon *et al.* (2005) established that depression was a key factor when they compared 100 individuals following moderate and severe traumatic brain injury with individuals following traumatic subarachnoid haemorrhage in relation to neuropsychological impairment and vocational outcome at one year. Individuals following traumatic subarachnoid haemorrhage had significantly worse vocational outcome, and although most of the data was self-reported in relation to mood, this study does further confirm the difficulty that post injury depression can pose although its applicability to the United Kingdom is limited. In France the findings of Bonneterre *et al.* (2013) somewhat support Hanlon *et al.* (2005). Bonneterre *et al.* (2013) established that the presence of mental illness or behavioural disabilities was the main factor limiting maintaining work with their 100 participants following traumatic brain injury, and suggested that support in the workplace was a key factor on returning to work, but again applicability to the United Kingdom is limited due to cultural difference and 80% of their participants being male.

In relation to gender and predicting return to work, Corrigan *et al.* (2007) in the USA explored if there were gender differences in employment one year post traumatic brain injury with 3444 participants (2487 men and 957 women). They found that women were

more likely to decrease their hours or stop working, except in their oldest participant group (55-64 years), and that women showed a better pattern for employment outcomes as their age increased. Again these results may have limited applicability as they may have been affected by the sample group including significantly less women.

Predicting return to paid work following a brain injury in the United Kingdom continues to be a challenge, and currently there is no measurement tool available. Evidence provides limited predictions for return to paid work relating to the presence of fatigue, in relation to age, injury severity, the presence of depression, presence of mental illness or behavioural disabilities and gender (Hanlon *et al.,* 2005; Corrigan *et al.,* 2007; Schonberger *et al.,* 2011; Bonneterre *et al.,* 2013; Waljas *et al.,* 2014). Further longitudinal research is needed to better understand how to more effectively predict successful return to paid work and to inform future rehabilitation.

2.8.3 Factors relevant to sustaining work

This theme explores sustaining return to work and invisibility and stigma following a brain injury.

2.8.3.1 Sustaining return to work

Four studies, although only Macaden *et al.* (2010) from the United Kingdom, carried out research relevant to sustaining return to work following a brain injury. Three, including Macaden *et al.* (2010), were small qualitative studies and Fraser *et al.* (2006) a larger study that used mixed methods. Factors established by these studies as relevant to sustaining work are: the ability of individuals to adapt, employers having personal experience of disability and reduced alcohol problems and injury status (Levack *et al.,* 2004; Fraser *et al.,* 2006; Macaden *et al.,* 2010; Soeker *et al.,* 2012b).

Levack *et al.* (2004) in New Zealand, found that their seven participants (four men and three women) following moderate to severe traumatic brain injury, on return to paid work had negative experiences ranging from clinical depression to facing disciplinary action, and that some were unable to adapt to their work resulting in job termination. In opposition to this in South Africa, Soeker *et al.* (2012b) explored the experiences of return to work rehabilitation programmes of 10 participants (nine men and one woman), and described that workplace adaptations enabled his participants to adapt to workplace demands and that ergonomic adaptations in particular speeded up the time they took to

complete tasks. Although interesting, both of these studies are small and the participants of Soeker *et al.* (2012b) were predominately men with mild to moderate brain injuries, so caution is needed before applying these findings.

A study in the United Kingdom related to sustaining work was carried out by Macaden *et al.* (2010), who explored factors affecting sustaining employment following an acquired brain injury. Although they only researched eight participants (seven men and one woman), they did use a multiple case study approach which included family members, job coach and co-workers, so attempted to triangulate findings. They established that employers with personal experience of disability helped participants, and that to sustain employment the injured needed unconditional motivation, insight and the ability to cope with cognitive and behavioural difficulties. Despite this being a study from the United Kingdom, it does have drawback generalisability, as it included a predominately male and small sample, all of the participants had received vocational rehabilitation and two of the participants had a cerebrovascular accident/stroke.

The largest study, carried out in the USA by Fraser *et al.* (2006), explored the role of job complexity following traumatic brain injury with 140 workers who had experienced mild to severe injuries, and who were predominately male and at three to five years post injury. They concluded that more research was required in relation to job complexity, but also that participants who were able to maintain complex work were more likely to be female, have fewer alcohol problems and be less severely injured. Unfortunately this study only examined one point in time and would have been more beneficial to have followed up participants.

This limited evidence does not provide a clear, nor reliable picture of how individuals following a brain injury manage to sustain work in the United Kingdom. It only infers that adaptation, employers' experience of disability and reduced alcohol and injury status may be relevant, therefore further research is required.

2.8.3.2 Invisibility and stigma

Three qualitative studies established findings relevant to invisibility (symptoms unable to be seen) and stigma following a brain injury, although only Gilworth *et al.* (2008) is from the United Kingdom. Gilworth *et al.* (2008) explored work related expectations and experiences of 33 workers (22 men and 11 women) who had sustained mild to moderate

brain injuries, and interviewed them at four to six months post injury. Their findings established that participants experienced difficulties due to the invisibility of their disability and a lack of advice. Most experienced a lack of support in the workplace and had no access to information about brain injury. This study could be significant despite it being from one single hospital in the north of England, including both early injury data and encompassing a wide range of injury severity. Stigma was also highlighted by 10 participants (nine men and one woman) to be the cause of loss of jobs and to be negative when obtaining new jobs in the study in South Africa by Soeker (2011), although again this is a small, predominantly male and wide ranging injury severity study. Also in a later study, Soeker *et al.*'s (2012a) 10 participants, following mild to moderate traumatic brain injury, reported feeling underestimated by society, feared unemployment and reported stigma related to their brain injury, therefore supporting the findings of Gilworth *et al.* (2008) in the United Kingdom and validating the earlier findings of Soeker (2011).

Although relatively weak evidence based, invisibility and stigma may be linked to sustaining work following a brain injury, but both require further investigation.

2.8.4 The meaning of work, quality of life and life satisfaction

This theme reviews two non-United Kingdom research studies in relation to the perception and meaning of work and one study from the USA in relation to perceptions of work, quality of life and life satisfaction.

2.8.4.1 The perception and meaning of work

Only two studies explored the experiences of those who attempted to return to work with emphasis on factors related to perceptions of success and failure and the ascribed meaning of returning to work (Levack *et al.,* 2004; Opperman, 2004).

Levack *et al.* (2004) in New Zealand, already briefly presented in the sustaining return to work theme, from their sample of seven participants (four men and three women) following moderate to severe traumatic brain injury, established that paid employment is indicative of a participant's success. Interestingly however success was reported by their participants even when paid work was not, and success in the workplace was associated with factors other than hours worked or pay earned. Their participants identified feelings of productivity as being a success and having a sense of having done something worthwhile, although this is of limited generalisability.

Very small qualitative case studies carried out by Opperman (2004) in the USA also described the perceived meaning of work for their two participants (both women, aged 31 and 46 years) following traumatic brain injury. These two participants described the meaning of work as both subjective and objective. One described work as a large part of who a person is because that is what the person does day in and day out, and the other participant described work objectively and as a means to get money to live and to pay bills. These findings are weak and not generalizable, but do demonstrate individuals' unique perception and meaning of work.

2.8.4.2 Perceptions of work, quality of life and life satisfaction

Two quantitative, non-United Kingdom studies explored perceptions of return to paid work, quality of life and life satisfaction following a brain injury (Johansson and Bernspang, 2003; Tsaousides *et al.,* 2009).

Tsaousides *et al.* (2009) in the USA examined how employment related to perceptions of quality of life with 427 participants following traumatic brain injury. They concluded that their participants' perceptions of employability related strongly to their quality of life, and that having increased confidence related to their sense of need attainment. This suggests that individuals following a brain injury need to have the confidence to be able to see that they may return to work in order to contribute to and improve their quality of life. Despite it being a large study, unfortunately no objective criterion was used to measure self-efficacy so it is of limited value on its own.

In Sweden, Johansson and Bernspang (2003) carried out a longitudinal study to assess the subjective life satisfaction of 36 participants following a brain injury and its relation to work re-entry after admission to a rehabilitation programme. They established statistically significant lower satisfaction at three years than at the second, six year follow up, and that significantly more participants were satisfied in the group that had returned to work. Although interpretation of these results is limited due to self-report and participants potentially having limited insight, they do suggest that over time potentially these participants were able to recover, adapt and improve their perceptions, quality of life and satisfaction by improving their chances of returning to work, but this requires further research.

Again this is weak evidence and not easily applicable to the United Kingdom, but it does imply that return to paid work is perceived as a success following a brain injury, however this success may be subjective as some individuals still reported success where they were not being paid and where they were contributing and felt meaningfully productive. It could be that engaging in work provided them with a positive sense of self-worth, but this requires further study. The meaning of work appears to be different to individuals. There may be a connection between individuals' self-confidence following a brain injury, their perception of being potentially able to return to paid work, their life satisfaction and their perceived quality of life, but these connections are not clear and currently have no research evidence within the United Kingdom.

2.8.5 Self-awareness and adaptation

This final theme reviews self-awareness, self-efficacy and self-identity and adaptation. There is some overlap, with some studies previously presented, between this theme and the previous themes factors impacting and predicting return to work and to sustaining work. These previously presented studies are referenced only within this theme as they have some application to self-efficacy and self-identity and adaptation but repetition has been avoided.

2.8.5.1 Self-awareness

It has been suggested by Ownsworth *et al.* (2006) and Ownsworth (2010) that the level of self-awareness following a brain injury can impact return to paid work, although this evidence is limited. In Australia, Ownsworth *et al.* (2006) carried out a 12 month longitudinal study exploring self-awareness and emotional well-being related to change in employment outcome with 50 individuals following acquired brain injury. They found that an increase in self-awareness was associated with participants' improved employment status, however this association is unclear, and low levels of self-awareness may not preclude individuals following a brain injury from returning to paid work. In addition participants in their stable employment group were significantly older than their improved employment group participants, so this may have influenced their results.

Again in Australia Ownsworth (2010) used descriptive case series to describe the implementation of a metacognitive approach for facilitating return to work of three individuals (two male and one female) following acquired brain injuries. Two of the

participants had road traffic accidents and traumatic brain injuries and one had sustained a cerebrovascular accident/stroke, so there are limitations in relation to the small sample size. What is of interest however is that the three participants achieved paid work within three to 16 weeks following their metacognitive training, which aimed to increase their self-awareness of post injury changes and their self-monitoring. This study implies that self-awareness can be improved, and that it could be a factor when returning to work after a brain injury, however it is not clear to what degree.

2.8.5.2 Self-efficacy and self-identity

Previously presented studies have suggested that following a brain injury an individual's self-efficacy and self-identity may be disrupted and affect return to work (Power and Hershenson, 2003; Soeker *et al.,* 2012a; Hooson *et al.,* 2013). Some injured individuals described a sense of loss of their former self and expressed uncertainty about their future (Soeker *et al.,* 2012a). The 10 participants (five male and five female) in the study by Power and Hershenson (2003) also reported challenges to their self-concept and that this manifests itself as a drop in their self-image. Power and Hershenson (2003) further reported that for their traumatic brain injured participants with a well-developed work ethic, loss of work led to a perceived loss of their value as a person, as well as loss of their self-confidence, and that their self-concept linked to their work adjustment and future career development. Most interestingly however in the previously presented study from the United Kingdom, Hooson *et al.* (2013) established that all their traumatic brain injured participants viewed working as a means to develop as a person, and to establish their identity that they based it largely on their earning ability. Despite these being small studies, they do suggest that individuals following a brain injury may use return to work as a vehicle to re-establish their self-efficacy, self-concept and self-identity.

An additional Canadian study by Petrella *et al.* (2005) explained that individuals following an acquired brain injury need to fight for their identity, and that this means struggling to maintain their sense of self, which involves pushing a set of beliefs about themselves based on their past lives, without taking into account changes caused by their injury. This small study had only six participants, but they had lived with their injuries for an average of 14 years, and its findings do suggest that it is important to provide self-efficacy building strategies whilst injured individuals explore changes to their sense of self but this requires further research.

2.8.5.3 Adaptation

This sub theme appears to be a continuation of the previous sub theme where it was suggested that individuals' self-efficacy and self-identity following a brain injury may be disrupted requiring adaptation. Two previously presented studies inferred that injured individuals need to adapt and rebuild themselves, and that they experienced feelings of loss on re-engaging in occupations (Soeker, 2011; Hooson *et al.,* 2013). Both Soeker (2011) and Hooson *et al.* (2013) are small qualitative studies with only 10 participants (both predominantly male) in each, in addition to including different injury severities, so do need to be viewed with caution, however this could be worthy of further research.

Soeker (2011) provided insight into the process of occupational adaptation in South Africa and how it may link to his participants' sense of competency and identity, and how they tried to rebuild themselves by finding contentment with their a/disabilities and rebuilding their self-concept and self-esteem. In his study the participants reflected that they needed to mentally separate from their previous life in order to adapt and attempt to continue with life. In the study from the United Kingdom, Hooson *et al.*'s (2013) participants reported their experiences of returning to work as being painful and experiencing a grief reaction when exploring re-engagement in their occupations. All of these participants viewed working as their means to develop as a person and to establish their identity based largely on their earning ability.

A study carried out in Sweden by Lundqvist and Samuelsson (2012) somewhat supports the need for adaptation, as it claimed that for their participants with an acquired brain injury it was important to have a fighting spirit, positive attitude, the ability to change, to take control of their life and to learn to cope with ongoing symptoms. They also suggested that it was important to have a job following their injury as it was a way to come back, to feel like they belonged and to feel that they could contribute to society. This was a qualitative sample of 14 (eight men and six women) and more importantly six of the sample group had had a cerebrovascular accident/stroke and only eight had an acquired brain injury, so application of the results has to be with caution. These three studies however do suggest that perhaps return to work is being unconsciously used as a vehicle to self-rediscovery following a brain injury. It appears plausible that these individuals may use work to redevelop, to re-establish their identity and to adapt their self-efficacy and self-concept, however this requires further investigation.

2.9 Limitations of the literature reviewed

The literature yield varied considerably due to the differing participant mix following brain injury included in the studies. There were also differences in the definitions of the research variables, the assessment and outcome measures used and the study designs. International literature was included, but weaknesses include there only being five studies from the United Kingdom and the use of various terms for return to work being used such as paid work and paid employment.

2.10 Chapter conclusion

The first part of this chapter established that huge health, social and economic impacts follow a brain injury, usually within a working age population. The Government in the United Kingdom has introduced National Service Frameworks and head injury quality standards, however it is unclear if and how these practically impact individuals returning to paid work following a brain injury, employers, the workplace or how their impact is currently measured (DH, 2005; 2012; NICE, 2014). Currently the occupational needs of individuals following a brain injury returning to paid work and the effectiveness of their vocational rehabilitation are unknown (Hocking, 2000a). Little is also known about if and how returning to paid work impacts their health and wellbeing. More research in the United Kingdom is needed regarding the barriers and success factors of returning to paid work following a brain injury to address the current loss of and impact on economic productivity and the financial, health and social burdens facing these individuals and our society.

The second part of this chapter, using five themes extracted from a review of relevant literature, established a baseline of the existing knowledge and evidence base in relation to the research. A study from the United Kingdom reported a 40% return to paid work rate, consistent with the global general outcome literature (Friedland and Potts, 2014). The evidence demonstrates that a low return to paid work rate following a brain injury is not isolated to the United Kingdom, and appears to be an international issue worthy of research (Shigaki *et al.,* 2009; Friedland and Potts, 2014). Despite similar return to paid work international rate outcomes, the recovery journey of individuals following injuries appears to vary in relation to the time it takes to return to paid work and the rehabilitation provided, and it is not clear if rehabilitation following an injury impacts return to paid work rates (Walker *et al.,* 2006).

Evidence established fatigue as an ongoing issue impacting return to work following a brain injury, but this requires further research (McCrimmon and Oddy, 2006; Rubenson *et al.,* 2007; Van Velzen *et al.,* 2011; Hooson *et al.,* 2013). Evidence suggests it is possible that cognitive difficulties, especially remembering and concentrating and anxiety and depression may impact return to paid work, but the severity, potency and management of these symptoms is currently not clear (Power and Hershenson, 2003; Franulic *et al.,* 2004; Bjorkdahl, 2010; Benedictus *et al.,* 2010; Artman and McMahon, 2013; Van der Horn *et al.,* 2013). Evidence provides limited predictions for return to paid work relating to the presence of fatigue, age, injury severity, the presence of depression and mental illness or behavioural disabilities and gender (Hanlon *et al.,* 2005; Corrigan *et al.,* 2007; Schonberger *et al.,* 2011; Bonneterre *et al.,* 2013; Waljas *et al.,* 2014). Further research is needed in the United Kingdom to be able to better predict successful return to paid work and to inform future rehabilitation. Furthermore, there is not a reliable picture of how individuals following a brain injury manage to sustain work in the United Kingdom, although weak evidence implies that invisibility and stigma may be linked, but these require further investigation.

Success was reported even when paid work was not achieved, and success in the workplace was associated with factors other than hours worked or pay earned. There could be a connection between an individual's confidence following a brain injury, the meaning and perception of being able to return to paid work, their life satisfaction and their quality of life, but again these connections are not clear and currently have no research evidence within the United Kingdom.

Level of self-awareness following a brain injury can impact return to paid work, although evidence to support this is limited (Ownsworth *et al.,* 2006; Ownsworth, 2010). Following a brain injury, an individual's self-efficacy and self-identity may be disrupted and affect return to work. Weak evidence suggests that individuals following a brain injury may use return to work as a vehicle to re-establish their self-efficacy, self-concept and self-identity, but this requires further research (Power and Hershenson, 2003; Soeker *et al.,* 2012a; Hooson *et al.,* 2013). It appears plausible that these individuals may use work to re-establish their identity and to adapt their self-efficacy, however this requires investigation of the lived experiences of return to work following a brain injury.

This chapter has provided a background, context and baseline of existing knowledge. It has also identified gaps in relation to the need to improve our understanding of the factors impacting return to paid work of individuals following a brain injury in the United Kingdom. Chapter three next explains the methodological approaches considered and the research methodology selected to carry out the research in order to provide an original contribution to increase and improve this body of knowledge and future practice.

Chapter 3 Methodological approaches

3.1 Introduction

Chapter one introduced the research rationale, the wider context, my research background and the research aims. Chapter two provided a more detailed background to the research and a baseline of existing knowledge. Chapter two also identified gaps in relation to our understanding of the factors impacting return to paid work following a brain injury in the United Kingdom, especially in relation to the lived experiences of the individuals involved.

This chapter explains the methodological research approaches that I considered, and the approach that I selected to underpin the development of the research, data collection processes and analysis. Following the research aims and objectives being established in chapter one, I considered and assessed the most appropriate approaches to carrying out the research. An explanation of my methodological learning, journey and a justification of my chosen methodological approach follow.

3.2 Methodological approaches considered

A methodological approach was required that would enable me to explore a potentially sensitive and difficult lived experience with both a vulnerable group of individuals following a brain injury, and employers of individuals following a brain injury. These individuals could have had either a positive or negative experience of return to paid work. My previous research experience had been predominately qualitative research approaches, and initially a more quantitative approach was favoured to expand my experience in this area. I quickly realised however that a randomised controlled trial or purely quantitative method would not facilitate the rich or deep data collection required. Following more focussed reflection of my research aims, I realised that I was not aiming to establish effectiveness of current return to paid work programmes or vocational rehabilitation, but that I was aiming to explore and to understand the factors involved in return to paid work, either positive or negative factors. I was aiming to understand the lived experiences of individuals, therefore I realised that a more qualitative approach was needed (Van Manen, 1990; Cohen *et al.,* 2007). I then decided that I needed to explore different qualitative approaches.

Initially, I considered ethnography as it can provide description, understanding and an explanation of a research area using the perceptions and views of participants. Ethnography produces descriptive cultural knowledge of a specific group, and of activities in relation to a particular cultural context from the point of view of members of that group, and can provide description and analysis of patterns of social interaction using 'insider accounts' (Cohen *et al.,* 2007, p.169). Using ethnography would have involved me participating in the daily lives of individuals and observing them over a period of time (Hammersley and Atkinson, 1995). I decided however that it was very unlikely that a large enough or strategic geographic community of participants following a brain injury, who had returned to paid work, would be available for ethnography to be effective. In addition, ethnography would require a wide database over a long period of time, and it was unclear at such an early stage of my research how successful recruitment of participants following a brain injury would be. There is also a very limited number of individuals following a brain injury who return to paid work within the United Kingdom, and it was unlikely that I would have unlimited access to those participants following their recruitment (Hammersley and Atkinson, 1995).

I also considered grounded theory, as it derives and constructs theory from data systematically gathered and analysed through the research process, with the researcher allowing theory to emerge from the data (Charmaz, 2014). Grounded theories, because they are drawn from data, are likely to offer insight, enhance understanding and provide a meaningful guide to action. Although limited research exists in relation to return to paid work following a brain injury, grounded theory is better suited to where there is a dearth of research literature or when building or testing a theory, therefore I considered it not to be the most appropriate to address the research aims, nor to describe the return to paid work participants' experiences (Strauss and Corbin, 1998). In addition, I needed a more descriptive understanding of the lived experience of return to paid work following a brain injury rather than an explanatory theoretical framework (Charmaz, 2014).

3.2.1 Occupational therapy and occupational science

Within the occupational therapy profession it is believed that individuals "need a balance between creativity, leisurely diversion, aesthetic interests, celebration and serious work and that this balance is essential to health" (Kielhofner, 1997, p.33). As I am an occupational therapist it is important to acknowledge that I view individuals as

occupational beings, and for this reason that I considered research approaches that could complement occupational therapy's philosophy. Occupational therapy views human beings as "complex, multileveled systems who act on and interact with their environments" so qualitative research approaches fit well with what occupational therapists want to know (Yerxa, 1991, p.199). McLaughlin Gray (1997, p.6) described succinctly how occupational science "arose in response to a period of crisis and change in occupational therapy resulting in it returning to the profession's roots-the concept of occupation". Work, as an occupation, can be a source of unique meaning to individuals, so it was important for me to identify a method that could truly capture the lived experiences of what returning to paid work meant to individuals and to go beyond a reductionist approach (McLaughlin Gray, 1997; Reed *et al.,* 2011). Phenomenology gets "to the essence" and the meaning of a phenomenon (Morse, 1992, p.91). After further reading and deeper exploration, I established that both the philosophy of phenomenology and occupational therapy together could view individuals as both occupational beings and at the same time allow the bringing together of both my professional identity, by researching within my professional life world, and the research lived experience of individuals and employers following brain injury (Morse, 1992; Finlay, 2011). At this point in the research journey it became clearer to me that phenomenology would allow the unique essence and meaning of work to be explored from each individual participant's lived experience, and at the same time focus on describing the phenomenon of return to paid work following a brain injury.

3.3 Phenomenology

Phenomenological philosophy was largely developed by Husserl in the late 19th century and later extended by philosophers Heidegger and Gadamar to study phenomena as they appear through consciousness (Becker, 1992; Finlay, 1999). Phenomenology is both a philosophy and a qualitative approach, and it involves "the description of one's experiences" (Hammond *et al.,* 1991, p.1; Creswell, 2009). The term phenomenology is partly derived from the Greek word "phainomenon" (plural; phainomena) (Spinelli, 2005, p.6). It was necessary for me to understand the experiences of individuals following a brain injury and their employers' experiences of returning to paid work. As phenomenology "addresses, identifies, describes, understands and interprets the experiences people have in their day to day lives, and precisely as those people have the

experiences and understand them", I accepted that this was potentially the best qualitative method for my research (Crotty, 1996, p.14). Phenomenology believes that phenomena are both humanly and consciously experienced, and phenomena are described by the participants and studied by the researcher. Phenomenological reflection is "not introspective but retrospective" and reflects on the lived experience that has already passed or has been lived through (Van Manen, 1990, p.10). Finlay (2011) has described phenomenology as seeking to do justice for everyday experience and to evoke what it is to be human, and that was exactly what I was aiming to achieve.

3.4 Selecting the most appropriate phenomenological approach

Phenomenology includes a number of approaches and traditions, so when I was selecting the most appropriate phenomenological method I needed to consider the chosen design and required outcome.

3.4.1 Husserlian roots

The Husserlian tradition (1859-1938) began the modern phenomenological movement (Husserl, 2001). Husserl introduced the concept of the life-world or the lived experience claiming that it is taken for granted, but that the task is to return to taken for granted experiences and to re-examine them (Koch, 1995). Husserl's transcendental phenomenology is concerned with the discovery of meanings and essences in knowledge. Transcendental phenomenology is bound up in the concept of intentionality which "is the orientation of the mind to its object and that the object exists in an individual's mind in an intentional way" (Moustakas, 1994, p.27). Husserl believed that every act of intentionality was made up of two experiential foci, which he labelled noema and noesis (Husserl, 2001). Noema is what is experienced and noesis the mode of experiencing. Noema refers to the directional element of experience, it is the object (the what) towards which individuals direct their attention and upon which they focus. Noesis is the referential element of the experience and is the mode (the how) through which individuals define an object.

3.4.2 Heidegger's hermeneutic 'interpretive' approaches

Martin Heidegger (1889-1976) was Husserl's colleague and successor, and he believed that intentionality is where "every thought is a thought of something, every desire is a desire of something and every judgment is an acceptance or rejection of something" (Crotty, 1996, p.39). It was Heidegger's shift from considering problems of epistemology

to the problem of ontology, for example what it is to be a human, which radically altered the modern debates on the nature of science and of knowing (Benner, 1994). Hermeneutics is the method for studying human beings that came from the Heideggerian view of a person and is consistent with it. This interpretive approach is called hermeneutics and suggests the bringing of understanding, particularly where language is involved. The goal of a hermeneutic or interpretive approach is to understand everyday skills, practices and experiences and to find commonalities in the meanings, skills or practices (Benner, 1994). Interpretative phenomenological analysis (IPA) is strongly influenced by Husserlian phenomenology, and is an inductive approach concerned with understanding an individual's personal account of an experience. Interpretative phenomenological analysis is used to develop in depth understanding of how individuals experience and ascribe meaning to a phenomenon (Clarke, 2009).

I had established that phenomenology could allow an in-depth exploration of how the return to paid work phenomena appeared to individuals following a brain injury and their employers, and the meaning(s) of this to them (Finlay and Ballinger, 2006). It could seek to understand and describe their behaviour, and to understand underlying meanings (Finlay, 1999). Six principles underlie all phenomenological approaches: a focus on the life world, a commitment to description over explanation, phenomenological reduction, an attempt to retain a non-judgmental attitude, acceptance of a role for interpretation and the concept of intentionality (Finlay, 1999). Having considered the range of approaches, I needed to further explore which phenomenological approach would be most and best suited to address my research aims.

3.5 The Husserlian approach

The Husserlian phenomenological approach initially appeared to fit the nature of my research aims, as its primary concern is not to explain the causes of things or events, but to provide a description of how things are experienced by those involved first hand (Denscombe, 2003). Initially the concept of phenomenological reduction was of concern as this is where researchers have to suspend temporarily their own beliefs and theories concerning the phenomenon under exploration, while concentrating on the experience (Giorgi, 2000b). I was unsure, after so many years of working with individuals following brain injuries, that it would be possible for me to abide by the rule of epoche and to bracket my beliefs (Giorgi, 2000b). I had to seriously consider if I would be able to bracket

biases or bracket a substantial number of them and be able to be constantly aware, during analysis, about how my beliefs may bias my view (Giorgi, 2000b; Smith *et al.,* 2009). McLaughlin Gray (1997) has likened bracketing to the mathematical operation of putting something in brackets, and it was necessary for me to give further thought as to how I could manage this.

Heidegger moved away from the Husserlian approach, and his interpretive or hermeneutic method of enquiry was a distinct move away from bracketing and pure description, towards a theory of the interpretation of meaning. It differed from descriptive phenomenology by attempting to interpret phenomena, by uncovering its hidden meanings, rather than uncovering and describing them (Holloway and Wheeler, 1996). Heidegger's approach doesn't seek to bracket the researcher's values and beliefs, but views these as necessary in understanding and making sense of participants' experiences. However this does run the risk of misinterpreting participant data and allowing pre-existing judgments to influence understanding of the research phenomenon (Clarke, 2009). Hermeneutical phenomenology shares with phenomenology a set of characteristic concerns i.e. the essence of being human, the life world, an understanding that is worked out in and through language and human existence (Silverman, 1991). The aim of phenomenology is "to transform the lived experience into a textual expression of its essence in such a way that the effect of the text is a reflexive re-living and a reflective appropriation of something meaningful" (Silverman, 1991, p.36). It became clear at this stage that if I used an interpretive approach that I would not need to consider bracketing, that an interpretive approach could facilitate understanding and would confirm commonalities, but not diversity, in the data.

Following a deeper comparison of the Husserlian descriptive approach and the Heideggerian interpretive methods, I reassessed the research aims in order to decide on the best and most appropriate of these two methods. The final selected research method needed to help me to explore and understand the factors which impacted the return to paid work of individuals following a brain injury. In order to do that, the different lived experiences of each of the participants and participant groups needed to be explored and the overall phenomenon described. By bracketing my previous clinical experience and pre-existing beliefs the Husserlian method would be feasible. I decided therefore that a Husserlian approach would be able to be used to answer my research aim, as long as my

central role could be recognised and reflected upon when exploring tentative data reflexively, and that I could "be open and meet phenomenon in a fresh way, which would involve dwelling with the phenomenon and bracketing (excluding or pushing aside) habitual ways of perceiving the world" (Finlay, 2011, p.23). This would however require deep reflection and critical concentration.

Further study about the Husserlian rule of description helped (Giorgi, 2000b). This is where the researcher aims to describe and not to explain as when using the interpretive method (Giorgi, 2000b). Study about the equalisation rule also helped, where the researcher reports in a descriptive manner what is consciously being experienced whilst avoiding any hierarchical assumptions (Giorgi, 2000b). Studying these aided my decision, and if I abided by these rules it would avoid any prejudice (Giorgi, 2000b). To be true to this method however I would have to bracket my past knowledge and withhold existential claims for the descriptions provided by the participants (Giorgi, 2000a). At this stage of methodological exploration Giorgi's descriptive method appeared to fit my research aims. It was necessary to establish the process by which the descriptions could be gathered if using this descriptive phenomenological method, and to also establish how my reflection and reflexivity could be enhanced to facilitate bracketing (Giorgi, 2000b).

3.6 Understanding the Husserlian approaches

It was necessary to understand how to apply philosophical phenomenology. Members of the Duquesne School, including Van Kaam (1966), Colaizzi (1978) and Giorgi (1988) have been faithful to the Husserlian approach. Van Kaam's style involves listening to descriptive expressions and preliminary grouping data into categories and ranking categories by the frequency of their occurrence (Van Kaam, 1966). Following reduction of the descriptive expressions into more precise terms this then allows a formulation of a hypothetical identification of the phenomenon. This appeared as too much of an overview and too broad an approach, as it was likely that it would only engage the most commonly occurring themes and not a variety or diversity of participants' lived experiences (Van Kaam, 1966). Colaizzi (1978) on the other hand, after reading descriptions, extracts significant statements, formulates meanings, organises the formulated meanings into clusters of themes and validates the description of each participant. Although this appeared an initial sound fit, it was by no means certain that it would be possible for participant descriptions to be validated and followed up following

data collection and transcription. The Giorgi (1988) method however allowed recorded transcripts to be read to get a sense of the whole phenomenon, to reflect on each transcript, identify meaning units in each transcript, to regroup and re-describe statements relevant to each meaning unit for each transcript and to reflect on each meaning unit across all of the participants to then uncover themes. This could then lead to the writing of an "exemplary narrative to illustrate each invariant theme" and to synthesise the statements (Crotty, 1996, p.22; Husserl, 2001). This would then allow me to describe the structure of the experience (Giorgi, 1989). For these reasons I selected the Giorgi (1988) method, as it appeared to be sensitive to my research aims, would collect descriptive data, would capture differing data and would offer a truly descriptive lived experience without having to validate data with the participants following transcription and analysis.

The Giorgi (2000b) method also appeared most faithful to Husserl's descriptive method, while being modified for application in the research context. I decided and planned to use Giorgi's four essential steps to data analysis, and to apply them within a descriptive research approach (Giorgi, 1989; 2000b; Spinelli, 2005). Giorgi's four essential steps were to firstly read the participants entire description in order to get a general sense of the whole statement. Secondly to return to the participant's original description a second time with the specific intention of discriminating meaning units from within the psychological perspective and with a focus on the phenomenon being researched. Thirdly to go through all the meaning units and express the psychological insight contained in them more directly. Fourth and lastly, to then synthesise all the transformed meaning units into a consistent statement regarding all of the participants' experiences.

Each description of the phenomenon is under scrutiny and is derived from many specific structures, and that makes it differ from other descriptions (Giorgi, 2000b). Giorgi (2000b) advocates that these specific descriptions have to be raised to a more general level if typical claims for the situation are to be established. When using Giorgi's method, the researcher does not return the findings from data analysis to participants for verification and it is the researcher's responsibility, not the participants, to do the phenomenological analysis (Kleiman, 2004). By this stage of the research I decided that a phenomenological approach was the best methodology for this research and the Husserlian descriptive approach, Giorgi (2000a), would form the basis of the approach. Giorgi explains that the

term phenomenon has a technical meaning and means "that which is experienced precisely as it is experienced" (Giorgi, 1989, p.41). Using the Giorgi (2000b) method of data collection and analysis, lived experience descriptions from individuals and employers following brain injury regarding return to paid work would be established and used to be able to understand and describe a general situated description of this overall phenomenon.

3.7 Reflection and reflexivity

Reflection and reflexivity are different but linked. Reflection has been defined as the "process of thinking about practice at the time or after the event", and reflexivity is the process that researchers use to critically analyse influences on their practice and potential consequences on their analysis and outcome (Taylor and White, 2000, p.198). Reflexivity is essential to generate sound research, and to analyse how knowledge is generated. It requires critical self-reflection of the ways that a researcher's social background, assumptions and behaviour impact upon their research (Finlay and Gough, 2003). Reflexivity includes reflection, but goes further to make us analyse our assumptions. This may include our social class, roles and gender, and how they impact upon our practice and knowledge claims. Reflexivity makes us continually reflect on both our interpretations and research.

To be reflexive I needed to be able to self-reflect, and to examine the potential influence that I had on my research. This would enable me to understand if my values, views or decisions impacted my findings (Streubert and Carpenter, 2011). I also needed to reflect and critically concentrate to effectively use bracketing to remove myself from the participant descriptions of their experience, whilst at the same time effectively interacting with them. I decided that I needed to keep a reflective diary in order to facilitate bracketing and reflection during each stage of the data collection and analysis. I also decided to use the reflexive approach, described by Finlay and Gough (2003), as both reflection and reflexivity were required to enable me to sustain ongoing critical reflection. This was necessary to facilitate acknowledgement of my background, assumptions, positioning and/or behaviour that could impact the research process (Finlay and Gough, 2003). Phenomenological researchers need to reflexively engage in their own subjectivity through both bracketing and reflexivity to be self-aware, but also to be constantly aware of the evolving relationship between participants and themselves (Finlay, 2011). An inner

dialogue was required to promote reflexivity and to "respond inwardly rather than looking inward" (Archer, 2010, p.5). The use of the reflexive approach, explained by Finlay and Gough (2003), also allowed ongoing and sustained self-reflection throughout the research in relation to intersubjective experiences which were relevant to the phenomenon and ongoing philosophical debates. This facilitated the discovery of meanings within the data as the analysis progressed (Giorgi, 1989).

3.8 Phenomenological reflection and analysis

Giorgi has stated that "analysis is where phenomenology makes its strongest contribution because as a philosophy of intuition it helps to demonstrate how the discrimination of meanings can be an intersubjective process" (Giorgi, 1989, p.45). This approach to analysis was to prove more difficult to carry out than to understand. The research processes and journey of this philosophy are poorly written about, but it was important for me to remember that the first step of this approach to data analysis is to obtain a description, not to explain and not to construct. This is what makes it philosophically different from other approaches. This approach and the application of it are explained in more detail in chapter four.

The approach to data analysis needed to be reflective for the essential meaning of the phenomenon to be understood. By formulating meaning units from the lived experience transcripts this would facilitate the free act of "seeing" meaning (Van Manen, 1990, p.79). Giorgi recommends reading the whole description and looking to see what is happening within the data, and if there are differences, to try "to make psychologically explicit the relevant aspects of the phenomenon and to then synthesise the transformed units into a harmonious structure" (Giorgi, 1989, p.52). Themes can then be established from the emerging meaning units to structure the lived experience, and they are used as tools to capture and to then get to the meaning of the experience. Each transcript sentence would need to be analysed in relation to what it revealed in relation to the phenomenon. Gadamer (1975) describes this part of the data analysis as questioning and answering, and this approach would be used to reflect on when the phenomenon themes were being initially formed. It would then be possible for me to understand the significance of the preliminary themes by asking if this was what the experience was really like. Essential themes would then be determined from incidental themes. Giorgi describes this stage as being where the researcher is able to "tie all the meaning units together in a good way

and where there's a kind of fittingness to it and (when) you can see the fundamental meaning" (Giorgi, 1989, p.57). Phenomenologists use the method of "free imagination variation" to verify whether an established theme belongs to a phenomenon essentially rather than incidentally (Van Manen, 1990, p.107). Free imagination variation would be used during analysis of the data to make distinctions between the essential and incidental potential themes.

The final stage of the data analysis would create a phenomenological text by using responsive-reflective writing. This phenomenological description would be an overall description of the phenomenon and would be composed of multiple descriptions. Writing this final and overall description would facilitate a deeper sense of the meanings embedded in the overall data. The final phenomenological description would be made up of many examples and would allow me to "see" the deeper significance, or meaning structures of the lived experience (Van Manen, 1990, p.127). Writing both of the research phase phenomenological descriptions would allow a distance to be placed between the lived experience and the existential structure of the experience and to have a deeper sense of the meanings within it (Giorgi, 2006). Responsive-reflective writing at this final stage of the analysis would allow the phenomenon to develop true depth and meaning and to facilitate my understanding (Van Manen, 1990).

3.9 Conclusion

This chapter has explored the different methodological research philosophies and approaches that I initially considered to carry out my research. A number of qualitative and in more depth phenomenological approaches and traditions have been explained and their rationales reviewed. A justification has been provided, further consideration of the chosen Giorgi approach and the potential challenges to both the research design and the required outcome (Giorgi, 2000b). Chapter four explains the research process and philosophical debate in relation to my research journey. Chapter four next explains how this approach to descriptive phenomenological research, developed by Giorgi (1985; 2000a; 2000b), was followed and carried out in both phases one and two and in the final analysis of the research to explore the factors impacting the return to paid work of individuals following a brain injury.

Chapter 4 Method

4.1 Introduction

This chapter explains my research journey and how the descriptive phenomenological approach, developed by Giorgi (1985; 2000a; 2000b), was systematically followed throughout my research to explore the factors impacting the return to paid work of individuals and employers of individuals following a brain injury. The chapter begins by presenting the ethical considerations, followed by an explanation of the approach I took to participant recruitment, data collection and data analysis. A more detailed explanation and justification then follows in relation to how I individually analysed data from both phases, and how both phase descriptive findings were used together to describe the overall phenomena whilst remaining true to the Giorgi approach (Giorgi, 2000b).

4.2 Ethical considerations

It was important for my research to include sound ethical principles, and to protect the rights of participants. To support the principle of beneficence I needed to ensure that participants would not be harmed, and that they would be treated with both dignity and respect (Streubert and Carpenter, 2011). Meara *et al*. (1996) advise researchers to embrace the virtues of prudence, integrity, respectfulness and benevolence. From my point of view, as an ethical researcher, I needed to ensure that I addressed these virtues, and be as transparent as possible to participants (Danchev and Ross, 2014).

To support the principle of autonomy I needed to obtain informed consent, and to assure participants that I would maintain confidentiality and anonymity (Streubert and Carpenter, 2011). Confidentiality and anonymity can be challenging to uphold as researchers are not always in control of recruitment, and especially if a very specific and small number of participants are recruited. I had to be mindful of this, make every effort to protect participant anonymity and confidentiality at all times, and to be clear to participants of any occasion where confidentiality would have to be breached, such as if harm was identified to them or others (Streubert and Carpenter, 2011; Israel, 2015).

Research ethical codes and guidelines have been developed to avoid harm, but have been criticised as having a tick box approach, and not always encouraging researcher in depth consideration (Bond, 2004). Research guidelines are based on important ethical

principles, but researchers cannot rely purely on them to ensure that they are conducting ethical research (Danchev and Ross, 2014). It was therefore essential that I also understood my research context and virtues to guide my ethical behaviour and critical moral responsibility.

My research was compliant with ethical guidelines and practice, and received ethical approval from the University Research Ethics Committee and favourable opinion from the National Health Service Research Ethics Committee via the Integrated Research Application System (Appendices seven and eight) and Independent provider approval (Research Governance Framework for Health and Social Care, 2001; Mental Capacity Act, 2005; School of Health Ethics Guidelines, 2008). Regional Job Centres and Independent brain injury services acted as recruitment gatekeepers by forwarding participant information sheets (Appendices nine and 10) and consent forms (Appendix 11) to potential participants (Smith *et al.,* 2009).

As phenomenological interviews can lead to increased levels of self-awareness, on designing my research approach, I put risk assessment and safety strategies in place to protect participant well fair and manage potential participant consequences such as increased feelings of anxiety or disclosure (Danchev and Ross, 2014). For these reasons I included a statement, in part two of both participation information sheets (Appendices nine and 10), clarifying that I would only break confidentiality if there was an immediate risk to the participant or someone else. Prior to data collection, in anticipation of any follow up being requested during interviews, I also made contact with both Headway United Kingdom, a national charity that works to improve life after brain injury, and a Regional Job Centre Disability Employment Advisor (Streubert and Carpenter, 2011). I identified named contacts within these organisations in the event I would need to refer any participant onto them, following the participant's consent.

I initiated an application for National Health Service Research and Development approval. Whilst this application was in progress for local National Health Services, participant saturation for phase one was achieved via Independent brain injury providers, therefore the Research and Development application was withdrawn.

4.3 Participant recruitment

Phenomenological sampling advocates small sample sizes (Clarke, 2009). My recruitment objective was not to make generalisations, but that the participants recruited were as homogeneous as possible to be able to explore the phenomenon shared by both research participant groups (Creswell, 2009; Finlay, 2011). Participants were recruited in order to establish their insights and to develop a full description of data, which could be used to develop future return to paid work services based on service user needs (Brocki and Wearden, 2006). Firstly, phase one aimed to recruit individuals who had experienced a brain injury and who had returned to paid work, and then secondly phase two aimed to recruit employers that had been involved in the return to paid work of individuals following a brain injury. Final sample sizes were dependent on when data saturation occurred for both phases one and two.

4.4 Table of participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria	Justification
• All participants needed to be over the age of 18 and to be able to consent to participate. • All participants needed to be cognitively able and to have sufficient communication skills to participate in an interview. • Injured participants would have sustained either a traumatic or acquired brain injury (tumour removal, subarachnoid haemorrhage, burst aneurysm) of moderate to severe severity (Glasgow coma scale score of 12 or below). • Injured participants would have returned to either full or part time paid work after their injury. • Employer participants would have experienced employees following a brain injury either returning to full or part time paid work. • All participants may have had either a positive or negative experience of return to paid work. • All participants must have had their experience within England.	• Individuals unable to make their own decisions. • Individuals unable to understand or speak English with a degree of fluency. • Individuals who had sustained a congenital brain injury, had a degenerative brain disease, had sustained a cerebrovascular accident/stroke or in unpaid work. • Individuals who had sustained a mild brain injury (Glasgow coma scale score of 13-15). • Employers who did not have direct contact or experience with an employee following a brain injury that had returned to paid work. • Individuals with a diagnosed psychiatric disorder.	• Adherence to the Mental Capacity Act (2005). • A baseline was determined and expressed within both participant information sheets and inclusion data that all participants needed to be able to make decisions about taking part, consenting and to have sufficient cognitive and communication skills to take part in an interview. • Individuals who had sustained a congenital brain injury, with degenerative brain disease, sustained a minor brain injury or cerebrovascular accident/stroke, usually have a different recovery and rehabilitation services to individuals following a moderate to severe brain injury (as within the inclusion criteria), therefore these individuals were excluded.

4.5 Phase one and two participant recruitment

Using snowball sampling participants following a brain injury were recruited via posters, recruitment letters, participant information sheets and consent forms being e mailed and/or provided to gatekeepers within Headway United Kingdom and Private Independent Brain Injury National Services (Cohen *et al.,* 2007).

Also using snowball sampling phase two employers, that had been involved in return to paid work with employees following a brain injury, were recruited via hard copy and web posters placed within Headway United Kingdom, Job Centres and Job Centre staff providing participant information and consent forms. In addition to phase one recruits passing these participant information sheets and consent forms on to their own employers (Cohen *et al.,* 2007).

On receipt of the participant information sheets (Appendices nine and 10) both phase potential participants were able to discern if they met the criteria to take part in the research. All potential participants made initial contact with me either by telephone, text or by e mail to discuss their suitability, and were able to ask questions about the research where further clarification was required.

During the verbal, text and/or e mail communication exchange I was able to assess the abilities of all potential participants in relation to them being able to make their own decisions, their communication skills, mental capacity and their suitability to take part in the research (Mental Capacity Act, 2005).

On fulfilling the inclusion criteria and on return of the signed consent form, I invited participants to take part in an interview and offered an interview date, time and location that were mutually agreeable. At this initial stage of recruitment it was clear to both potential participants and I if potential participants were unsuitable by going through the participant information checklist and inclusion criteria. Suitability was generally decided and agreed by both the potential participant and I on discussion of the criteria.

Several potential participants who had sustained brain injuries were unable to take part as they were either doing voluntary work, had sustained a cerebrovascular accident/stroke or were in unpaid employment. Several potential employer participants

were unable to take part as they had experience of long term disabilities, but these were not related to traumatic or acquired brain injury. In these situations I explained the reasons why I had established my inclusion criteria and thanked those individuals for their interest and support.

Three employers in phase two were recruited from snowballing directly from the phase one participants who had sustained brain injuries. Following their own research interview, these phase one participants informed their employers about phase two of the research (Cohen *et al.,* 2007).

Phase two employer recruitment proved to be more challenging, took twelve months and wide recruitment across a large geographical location within England. This was necessary for me to acquire a sufficient sample, and for data collection and analysis to reach saturation. Reactions varied across potential employer recruits, and it became evident that some employers appeared suspicious of my research. This could potentially bias the nature of the employer data that I collected. This employer suspicion and anxiety may have excluded the collection of data from less motivated employers and employers who were experiencing acute return to paid work challenges that they appeared not to want to discuss in a research interview.

4.6 Data collection

All data were collected within England to allow me to practically access all participants. In relation to my safety during data collection, before I set off for each interview, I left in a locked drawer a sealed envelope marked confidential. The envelope contained the relevant individual participant's contact details that only one of my work colleagues could access. I instructed my colleague to only access and open the envelope if I failed to contact them at my time of return from that interview. I was able to dispose of each envelope on my return after each interview.

Phenomenological data is usually collected during an unstructured interview where "one open ended question is asked at the beginning of the interview and then develops other questions from participant's responses" (Becker, 1992, p.38). My data collection aimed to discover the phenomenon exactly as it appeared in the participant's experience, and my participants were viewed as experts and I viewed myself as a learner (Wilding and Whiteford, 2005). The interviews appeared paradoxical as they were structured yet

unstructured. I was prepared and knowledgeable yet open minded, and was immersed in the data yet had to stand back to get an overview. I used a multi-faceted opening question to start the interviews. All interviews responded to the research aims, but a few became semi-structured where participants digressed and I needed to return their focus to the research. The interviews were a "two way process where the researcher and participant" explored the lived experience of return to paid work (Taylor, 2005, p.39). The interviews continued until the participants had finished or exhausted their descriptions (Crotty, 1996). It was necessary for my preconceptions to be bracketed and for me to keep past personal experiences separate from those described by the participants, as this allowed the conceptual world of the participants to be exposed and for it to be fully understood (Giorgi, 1989; Finlay, 1999). The use of my reflective diary proved essential during both phase data collection stages as it allowed my reflection and reflexivity of the participant experiences and to detach my own experiences from these (Finlay, 1999; Finlay and Gough, 2003; Archer, 2010).

4.7 The interviews

The interviews were informal yet professional. Although I was not able to set interview rooms up myself, I was able, prior to each interview, to arrange access to quiet and private rooms to allow each participant to feel at ease.

I used an open-ended question for both phase one and two interviews which involved me actively listening and asking further questions when clarification was required. For example where a participant began to generalise about their experience it was necessary to insert a question that turned the discourse back to a level of concrete experience such as "can you give an example or what was it like?" (Van Manen, 1990, p.68). The interviews aimed to facilitate interaction, which permitted participants to tell their own stories in their own words. Each interview lasted between 45 to 60 minutes (Smith *et al.,* 2009).

I was very aware of being a researcher and a data collector, and in several of the interviews it was challenging not to be in my therapist role (Finlay, 1999). This was most noticeable where participants became upset or during the interview it became apparent that they needed therapeutic advice. Following reflection, I decided that I needed to manage my researcher/therapist tensions. I decided to let the participants describe their experiences, but if required on completion of their interview, I then recommended follow

up support services that they could access if they wanted to (Finlay and Gough, 2003). All interviews ended positively and I was thankful of the time each individual spent with me to share their experiences. Several interviews, where unpleasant, sad or work conflict experiences were shared with me left me feeling sad, upset and powerless. Following these experiences my PhD supervision and reflection helped me to be reflexive and to manage my upset and to see how these experiences fed into my research (Finlay, 1999; Finlay and Gough, 2003).

4.8 Phase one participants and interviews

Sixteen participants who had sustained a brain injury were recruited, consecutively interviewed and their lived experiences explored. Participants were viewed as experts and any of my preconceptions were bracketed within my reflective diary before carrying out the unstructured, recorded interviews (Crotty, 1996; Finlay and Gough, 2003). Phenomenological interviewing involved me asking one open-ended trigger question at the start of the interview and continued until participants had finished their descriptions. Most phase one interviews took place at Headway House locations within England. These locations were in Headway premises within the Headway United Kingdom organisation, which provides day centre environments to assist in the long term rehabilitation, respite care and hospital liaison required following a brain injury. The remainder of phase one interviews took place at the home of each participant.

Ten male and six female individuals who had sustained brain injuries participated in phase one. Eleven participants had an acquired brain injury and five a traumatic brain injury. The participants' median age at the time of their injury was 37 years of age and their median age at the time of their interview was 47 years. Fifteen of the participants had received acute rehabilitation whilst initially hospitalised and one participant received no rehabilitation. Only two of the participants had received follow up rehabilitation as out patients. Their time in general rehabilitation varied, and if calculated in four week months, was a median of 12 weeks. Thirteen of the participants had no vocational rehabilitation and only three had, but this was limited to brief periods of time for two of the participants in an occupational therapy department and for one a visit to a disability resource centre. Only one of the participants had left school with no qualifications, nine had achieved General Certificates of Secondary Education (GCSEs), one had completed a foundation art course, one a Business and Technology Education Council (BTEC)

certificate and four of the participants had undergraduate degrees. Seven of the participants were married at the time of their interview, three were single, four divorced and two were living with partners. Twelve of the participants described a positive economic climate at the time they were trying to return to paid work and four remembered a more difficult economic climate. Most participants reported living in more independent living accommodation than prior to sustaining their brain injury and some, following their injury, described less physically active hobbies. The phase one participants represented a wide range of paid work jobs and settings including a global banker, weed sprayer, apprentice engineer, railway clerk, travel agent, train driver and classroom assistant. Appendix 12 provides a tabulated demographic summary of the phase one participant data. Interestingly three phase one participants had been self-employed prior to their injuries, but had gone on to do different jobs. An example of a phase one interview transcript is also presented in Appendix 13.

4.9 Phase two participants and interviews

Eleven employers with experience of individuals following a brain injury returning to paid work were recruited, consecutively interviewed and their lived experiences explored. Phase two interviews mostly took place within the workplace of each employer, and only two interviews carried out at the home of each employer. Four male and seven female employers participated in phase two. The employers represented and came from a diverse range of organisations including: the public sector, international banks, schools, global IT, small business, charities and one was a self-employed Formula one trainer. They individually and collectively described the experiences of 10 male and one female employee who had sustained brain injuries. The employers described that five of the 11 injured individuals that they worked with had sustained an acquired brain injury and six had sustained a traumatic brain injury. The injured employees that the employers described had a median age of 35 years at the time of their brain injury, a median age of 49 years at the time of the employer interviews and a median time of 12 months away, on sick leave absence from work. Eight of the employees described had acute hospital rehabilitation such as attending a Headway House, acquired brain injury team intervention, counselling, orthopaedic follow up or physiotherapy. Only two of the employees had received vocational rehabilitation and nine had none. Of the 11 employees described, three had left school with no qualifications, three had achieved

GCSEs, two had completed apprenticeships and three had undergraduate degrees. Five of the employers described a positive economic climate at the time that their employee returned to work and six remembered a more difficult economic climate. The employees, described by the employer participants, represented a wide range of paid jobs including an administration assistant, postman, financial manager, learning assistant, factory worker, teacher, IT consultant, IT analyst, bus driver and Formula One trainer. Appendix 14 provides a demographic summary of the phase two participant data. A phase two interview transcript is also presented in Appendix 15.

The data I collected from both the phase one and two interviews contained many conversations and all interviews were transcribed verbatim. Husserlian approaches emphasise the need for phenomenological reduction (Giorgi, 2000a). Epoche required me to suspend or bracket any theoretical and preconceptions in order to prevent them from influencing my research, and to allow for the clear perception of the essential image or 'eidos' to be revealed (Finlay, 2011). I was very aware of being an instrument for data collection and was aware of reflexively "opening up a distance" between myself and my research circumstances to facilitate truly bracketed interactions with the participants whilst collecting data (Archer, 2010, p.9). For this reason, whilst transcribing the interviews, I also recorded my reactions in a reflective diary following each interview and transcription to ensure true description (Finlay and Gough, 2003). This was to prove most useful during data analysis which is explained in more detail below.

4.10 Phase one and two data analysis

Descriptive phenomenological analysis was used and, as previously explained in chapter three, the guiding theme of phenomenology is to go "back to the things themselves" (Giorgi, 1985, p.8). The purpose of the data analysis was to "grasp the essential meaning" of the data collected and to reflectively and reflexively clarify and to make explicit the structure of the meaning of the lived experiences (Van Manen, 1990, p.77; Finlay and Gough, 2003). In order to achieve this I used the four essential data analysis steps described by Giorgi (1985) by firstly reading the entire transcripts to get a general sense of the whole statements, then going back and reading them again to discriminate meaning units from the psychological perspective and focus of the research. I read the transcribed interviews several times to gain a feel for the content. I then extracted phrases or sentences that directly pertained to the research phenomenon in order to

collect a list of significant statements from each participant transcript. Early analysis involved me dwelling on the "exact words and meanings of each individual to uncover salient features of the phenomenon" (Becker, 1992, p.42). All 16 interview transcripts from phase one and 11 transcripts from phase two were read and significant statements extracted to formulate meaning units in relation to the participants experiences, but at the same time staying as close to the participants words as possible (Colaizzi, 1978; Giorgi, 2000b).

Formulating the meaning units was like formulating an understanding and is not a rule bound process but a free act of "seeing" meaning (Van Manen, 1990, p.79). Following delineation of the meaning units I then went through all of them and expressed the psychological insight contained in them more directly, especially for meaning units most relevant to the phenomenon (Giorgi, 2000b). Finally I synthesised all the transformed meaning units into a consistent statement regarding the participants' experience. Formulation of meanings from what was said to what was meant is the most precarious interpretative part of the process, and it was necessary for me to remain true to statements at the same time as drawing out their embedded meaning (Spinelli, 2005). Once I formed meanings from all the significant statements from all the participants the aggregate formulated meanings were organised into clusters of themes. A list of thematic elements was then integrated into an exhaustive core description of the phenomenon (Giorgi, 2000b).

This very much differs from an interpretive phenomenological analysis perspective, which adopts both emic (insider) and etic (interpretative, outsider) positions (Clarke, 2009). The emic position enables researchers to hear and understand the participant's story and place their experiences at the centre of their account. The etic position involves researchers trying to make sense of data by bringing in their own interpretations and theoretical ideas whilst using verbatim quotes to ground those interpretations in the participant's experiences (Clarke, 2009). This was the biggest difference of my research data analysis approach, and why reflexivity and the use of my reflective diary was important to ensure that my personal experiences and prior understanding did not influence the data analysis (Benner, 1994; Finlay and Gough, 2003; Clarke, 2009; Archer, 2010). The meanings were then aggregated into clusters of themes and referred back to the original transcripts for validation and to create description. Appendix 16 and 17

respectively present the phase one and two final meaning units and the emergence of each of the phase one and two themes.

When analysing the phenomenon, it was important for me to try to determine what the themes were, and the experiential structures that made up the experience. In seeking meaning we try to unearth something "telling, something meaningful, something thematic in the various experiential accounts we work at mining meaning from them" (Van Manen, 1990, p.86; Giorgi, 2000b). Themes are the tools for getting at the meaning of the experience. I regrouped and re-described statements relevant to each meaning unit whilst reflecting across all the transcripts to uncover themes which facilitated the writing of a psychological insight of the return to paid work experience, an idiographic portrait of an individual following a brain injury and an employer (Giorgi, 1989). The resulting idiographic portraits are presented in Appendix 18 for the phase one individuals following a brain injury and in Appendix 19 for the phase two employer participants.

Van Manen (1990) claims that expressing the overall meaning of a text is a judgment call and that different readers might discern different meanings. This makes no interpretation truer than another, but at this stage my bracketing was totally essential so as not to interpret but to describe the themes in relation to the research aims (Finlay and Gough, 2003). To determine the essential themes from the incidental themes it was important for me to make a distinction between them, as when reflecting on the phenomenon not all meanings are unique to that phenomenon. I used the method of free imagination variation to verify whether each potential theme belonged to the phenomenon essentially rather than incidentally (Van Manen, 1990; Giorgi, 2006). Six themes across 61 meaning units were established and analysis decisions recorded for phase one, followed by a further six themes across 50 meaning units being established from phase two data. General situated structures and descriptive summaries of return to paid work following a brain injury were then established for both of the phases and reflected all of the participants lived experiences. Wertz's (1985) study provided a useful template for presenting each summary structure in an organised and coherent way. Appendix 20 contains the general situated structure and descriptive summary of phase one and Appendix 21 presents the general situated structure and descriptive summary of phase two.

A reflexive approach was used and a reflective diary kept throughout the analysis process to increase awareness of any of my personal preconceptions in order to avoid influencing the analysis (Finlay and Gough, 2003; Clarke, 2009; Archer, 2010). The themes emerged directly from the data and are combined with direct quotes to understand the participants' lived experiences. Colaizzi (1978, p.58) claims that the success of all phenomenological research questions "depends on the extent that they tap the participant's experiences of the phenomenon as distinct from their theoretical knowledge of it". At this stage of the phase one and two data analysis the research aim to explore and describe the factors which impact return to paid work of individuals following a brain injury had been achieved. It was possible to establish themes for both phases one and two from collapsing and clustering the meaning units into themes that described the psychological insight within them. Van Manen (1990, p.88) claims that "a good theme formulation somehow seems to touch the core of the notion we are trying to understand", and following reflection I felt at this stage in the analysis that this had been achieved. The combined descriptive findings from both phase one and two are presented in chapter five.

4.11 Continued use of a reflective diary and reflexivity

The continued use of a reflective diary and reflexive approach helped me to observe, reflect and critically appraise the impact I was having on my research, and at times the impact that the research was having on me (Danchev and Ross, 2014). This involved me reflecting before and after each interview, and throughout the data analysis. This reflexive process increased my self-awareness, sensitivity to participant circumstances, and helped me to more clearly appreciate the experience of each individual participant. My reflexive analysis included exploring my cultural, political and social context, and this helped me to position myself in relation to my research and participants (Bryman, 2012). An example of this was my decision to introduce myself to participants in the role of researcher and not as an occupational therapist. This facilitated a more relaxed relationship and atmosphere between me and the participants. They were more open, trusting and able to describe their experiences. A further example, previously referred to in section 4.7, was my decision about how to deal with my emergent researcher therapist conflict, especially in interviews where participants described situations that warranted therapy input. Following both reflection and reflexive analysis, I put strategies in place

and decided to recommend, where relevant, therapy follow up options to participants following those interviews. I also decided to debrief in PhD supervision sessions with my supervisors, and explore the impact that upsetting participant descriptions had on me. This helped me to be more objective about how their descriptions impacted me and fed into the research, and to critically reflect on my social positionality. It also helped me to bracket the impact that my feelings had on the data collection, analysis, findings and conclusions. I had to continually juggle bracketing my knowledge and experience of brain injury, and to avoid making judgements about difficult experiences or poor treatment that participants had experienced. Reflexive analysis allowed me to interrogate the process that I used to understand each experience described (Taylor and White, 2000). This required effort to ensure that my contexts did not directly impact the data collected or analysed, and that I critically appraised my assumptions. Although I contributed to the construction of new knowledge, through using bracketing I attempted to minimise the impact that I had on it.

My reflective diary and reflexive approach proved most useful when approaching the final overall analysis of the research (Finlay and Gough, 2003; Archer, 2010). At the beginning of the data analysis of phase two I reconsidered the use of interpretative phenomenological analysis to analyse the employer data (Smith, 1996). This proved to be challenging and provided a philosophical debate for me, but following reflection I decided that to be true to the employer descriptions it was necessary to continue with the same descriptive data analysis, as described by Giorgi (2006) and as used in phase one, to complete the analysis of phase two (Finlay and Gough, 2003; Archer, 2010). Yet again I judged Interpretative phenomenological analysis to be too open to my interpretation at both phase one and two stages, as it encourages researchers to cluster and make sense of the data to explain it rather than to describe it and to be true to the participants' individual experiences. In relation to reflexivity, as I continued, it became apparent that I needed a critical awareness of anything that "could contribute to the search for answers" to the research aims so nothing important would be missed (Finlay and Gough, 2003, p.49; Archer, 2010).

4.12 Responsive-reflective writing

An overall phenomenological description is made up of many examples and allows us to "see" the deeper significance, or meaning structures of a lived experience (Van Manen, 1990, p.127). During the writing of the phase one and two phenomenological descriptions, both individually and separately, this allowed me to place a distance between the lived experiences and the existential structure of the experiences and to gain a deeper sense of the meanings within them (Giorgi, 2006). Van Manen (1990, p.152) believes that "responsive-reflective writing is the very activity of doing phenomenology". It was during this writing stage of the data analysis that I developed true depth and meaning in relation to the phenomenon, and this facilitated a much better understanding of it. I also became acutely aware however that both phase one and two general situated structure descriptions and data sets needed to be combined, to be able to provide an overall and total description and meaning of the complete phenomenon (Van Manen, 1990).

4.13 Explicating the whole

Explicating is a phase of synthesis and integration where emergent themes are pulled together into larger themes. Finlay (2014, p.122) has described explicating as "pulling together individual analyses" and this examines which meanings can be woven into a rich description of a phenomenon. When carrying this out it is important for researchers to be true to the phenomenon and not to merely theme the concepts. It was through explicating the whole that the final overall and combined phase one and two general situated structure and story of the overall phenomenon of return to paid work following a brain injury emerged (Finlay, 2014). This process helped to combine both phase one and two general situated structures, by me searching for connections across both phase one and two data and clustering the essential meanings. This allowed the overall phenomenon to be explicated and further analysed (Giorgi, 1997; Finlay, 2014). This final and combined general situated structure is presented at the end of chapter five and follows presentation of both the phase one and two individual descriptive findings.

The reflexive process involved during this stage of analysis resulted in some further philosophical debate, challenges and changes to my thinking, in addition to questioning any subjectivity. The use of reflexivity at this stage was not as a methodology but as a "mode of consciousness" which helped to create separateness between me and the

research data (Finlay and Gough, 2003, p.99). There next follows an explanation of the methodological reflection and journey that I took following the final general situated structure and story of the phenomenon being explicated, and clarification of the philosophical challenges I experienced whilst using and remaining true to the Giorgi approach (Giorgi, 1997).

4.14 Reflection and re-evaluation of the research aims and objectives

My research had originally aimed to explore and understand the factors which impact on return to paid work from the perspective of individuals following a brain injury and employers, and to improve return to paid work rehabilitation for people with an acquired or traumatic brain injury. The research objectives had planned to establish potential barriers and success factors from both phase research participants lived experience data. Following both phase general situated structures and stories of the phenomenon of return to paid work following a brain injury being established, I once again reflected upon and re-evaluated my research aims and objectives and the themes within each phase story of the phenomenon.

By this stage in my research I acknowledged that the phenomenon had been successfully explored and the barriers and success factors established from the participant data. The barriers and success factors had been understood to a degree but, following re-evaluation of the findings, I realised that one of the research aims and the fourth and final research objective had only been partly achieved. The remaining aim and fourth research objective had set out to improve return to paid work rehabilitation for people with an acquired or traumatic brain injury and, whilst awareness of the barriers and success factors involved had now been established, it was still necessary to turn this new understanding into actively improving future practice. I also realised, in addition to the need to improve return to paid work rehabilitation that, despite understanding of the factors involved being established from the 27 participant descriptions, that I needed a deeper meaning of the overall findings to inform future return to paid work rehabilitation. This deeper meaning would make the research findings more explicit, make further sense of them, lead to a deeper understanding of them and contribute to the emergence of a conceptual framework that could improve return to paid work rehabilitation. I realised that further phenomenological analysis of the final general situated structure needed to take place to

be able to fully understand and express the essence and meaning of the overall phenomenon to inform future practice (Giorgi, 1997; Husserl, 2001).

4.15 The ongoing methodological journey

In order to fully understand the essence and deeper meaning within the overall descriptive phenomenon it was essential for me to again use free imaginative variation which is "a natural method for discovering essences" (Giorgi, 1997, p.242). Free imaginative variation was again used and had previously facilitated my writing of the integrated and combined description and essential characteristics of the overall phenomenon (Giorgi, 2006; Finlay, 2014). In addition reflexivity allowed me to be immersed in the data and the research process but also allowed the ability for me to "to draw back and to contemplate what was occurring" (Finlay and Gough, 2003, p.62). With the help of free imaginative variation I was able to search for more essential meanings within the final general situated structure. This was the approach I adopted to search for and to establish meaning to enable deeper understanding and meaning of the research findings. Continuing to adopt a Giorgi and descriptive approach to the overall phenomena at this stage however proved to be the most challenging stage of the research, as descriptive phenomenology seeks the "normative and essential structure of the phenomenon and requires a focus on the interdependent constituents of the phenomenon's structure" rather than a thematic analysis favoured by interpretive phenomenologists (Wojnar and Swanson, 2007; Finlay, 2014, p.138). This was challenging because on completion of the writing of phase one and two descriptive findings and the final general situated structure, it became apparent to me following reflection, that whilst descriptive phenomenology had effectively described the findings in relation to the research aims it hadn't fully explained the true essence or meaning of the findings, nor examined the wider, contextual and deeper features of the experience (Lopez and Willis, 2004).

4.16 The philosophical challenges

Gadamer (1975) believes that "to understand is to interpret" and one of my research aims was to understand (Silverman, 1991, p.6). Heidegger believes that "language and understanding are inseparable and that it is only through interpretation that our being in the world becomes manifest and can be understood" (Finlay, 2011, p.52). Heidegger's approach to the study of human existence has been described as hermeneutical meaning

and this is where interpretive steps are taken between previous understanding and a new developing understanding between researchers and data. In hermeneutic phenomenology there is a shift away from description towards interpretation and it moves beyond description of the experience to seek meaning (Finlay, 2011; Reiners, 2012).

At this final stage of the data analysis methodological tensions arose for me as hermeneutical understanding is not free of prejudice but "facilitates understanding to be themed and to prove itself in relation to a phenomenon in the course of analysis and developing hermeneutic awareness" (Bleicher, 1980, p.183). Hermeneutic interpretation believes that researchers cannot remove themselves from the meanings established from the data. It was important for me to manage these tensions, and this period required further and deeper reflexive analysis in relation to my experience and deepening methodological awareness (Finlay and Gough, 2003; Archer, 2010). My researcher awareness further developed in relation to where I sat on the descriptive interpretive continuum, and I realised that the Giorgi descriptive approach remained the same and would always limit itself to the data that it provided. The Giorgi descriptive argument is "that sufficiently rich description would include an intrinsic account of the phenomenon" (Giorgi, 1997, p.242). Whilst this was reassuring a deeper understanding of the meaning and essence of the findings was still needed to completely fulfil my research aims and objectives.

4.17 Emergence of the four themes

This section presents and justifies how the essence and meaning of the phenomenon and the four final themes emerged (Giorgi, 1997). Giorgi strongly advises that researchers should choose one methodology and stick with the logic it proposes (Giorgi, 1997). It was important to me to remain true to the research participants and that the emerging essence and meaning should be grounded in the descriptive data. This was not an informal process but a descriptive one, and to be further and continually true to Giorgi's descriptive methodology I considered it important to "stay with the evidence regardless of how it presented itself" (Giorgi, 1992, p.125). For this reason I decided to go back and to further explore the research findings as they were described by both phase participants within the final general situated structure and the seven themes contained within that structure. I needed to do this to establish meaning and "insight into the

essence of the concepts involved" and that would add a further theoretical perspective and meaning to the lived experiences and the phenomenon (Husserl, 2001, p.79). The seven themes contained within the final general situated structure are presented at the end of chapter five.

Interpretation surrounds us, and this was not helped by a lack of philosophical phenomenology being translated into philosophical fundamental concepts and research guidelines (Giorgi, 2006). Interpretation is more common than description, but "description should have epistemological primacy because of its consistency with respect to evidence" and "if it is ambiguous" it should be described as such (Giorgi, 1992, p.131-2).

I reviewed the seven themes within the final general situated structure and by that stage also my newly written background and context chapter. I analysed the background and context data alongside relevant emerging theory and wider research literature. This was generated from background reading, whilst searching for deeper description and depth around emerging essences. I was looking to describe meanings within the data, not to explain them, to include diversity, and to include only the participants' descriptions not my own. This was not a thematic or interpretive analysis but a continuous process and a focus on the interdependent constituents within the final general situated structure, background and context, related and emerging research and theoretical essences that were emerging (Giorgi, 1997). These multiple descriptions and their integration aided me to establish deeper meaning, as well as to bridge and bring them together to provide a collective synthesis of the experiences. It was necessary for me to work back and forth between these data sets looking for descriptive links, relationships and embedded meanings, and for me to refrain from interpreting or explaining findings but to remain grounded in the data and to describe the meanings.

Four themes emerged following these analyses which reflect the deeper meaning of the seven descriptive themes within the final general situated structure. The four themes formed to express the essence and meaning of the phenomenon following free imaginative variation, responsive reflective writing, and categorial intuition of this descriptive data (Van Manen, 1990; Giorgi, 1997; Husserl, 2001; Giorgi, 2006). I used free imaginative variation to verify the core essences and embedded meanings of the data and

to contextualise features of the experience (Van Manen, 1990). Using responsive-reflective writing during my writing up of the phase research findings and the background and context chapter, as explained above, facilitated a deeper sense of the meanings embedded in the overall data, and by this final stage of analysis allowed the phenomenon to develop true depth, significance and meaning of the lived experience (Van Manen, 1990).

I continued to look for meaning within the data. From a phenomenological perspective this stage is known as categorial intuition, and this provided understanding of the phenomenon as a whole (Giorgi, 1989; Giorgi, 2000b; Husserl, 2001; Giorgi, 2006). Husserl (2001) believes that for categorial intuitions to function that researchers need to aim to look for essences and meanings that would potentially fulfil their need or frustrations. These exposed essences and meanings can then be synthesised. In the search for meaning of the phenomenon phenomenological analysis continued, Husserl (2001, p.88) refers to this approach as looking for "logical concepts, as valid thought-unities" and advises that these "thought-unities" must come from a researchers intuition. I searched for relationships within the descriptions that could lead to a deeper knowledge and fundamental clarification of the phenomenon (Husserl, 2001). Meanings were exposed following a return to the analytically explored connections between what Husserl (2001, p.90) refers to as "meaning-intentions and meaning-fulfilments". This phenomenological analysis resulted in essences becoming exposed and meanings being clarified. The resulting phenomenological unity then provided evidence of the meaning and I was able to then finally appreciate the most important components of the phenomenon (Husserl, 2001).

The four themes that formed express the essence and meaning of the phenomenon (Husserl, 2001). They provide a collective synthesis of the lived experiences, a deeper meaning and an understanding of the return to paid work following a brain injury phenomenon. The four themes are: occupational needs; experiencing loss, grief and adjustment; self-identity; and social inclusion and return to the workplace. These four themes are presented and discussed in depth in chapter six.

4.18 Trustworthiness and verification

Trustworthiness has been promoted with raw data being made available for scrutiny. Giorgi (2000a) claims replicability is possible either by having another researcher re-

perform the analyses already done or by having other researchers in other places obtain new descriptions of the same phenomenon and applying the same method, enabling them, in principle to come up with the same findings. Giorgi (1988, p.173) states that "if the essential description truly captures the intuited essence, one has validity in a phenomenological sense". Verification was also enhanced with another phenomenological researcher and PhD supervisor checking 50% of the data analysis (Crotty, 1996).

4.19 Conclusion

This chapter has explained step by step how I used Giorgi's descriptive phenomenological approach (Giorgi, 2000b). I have explained how I used this approach, in both phase one and two, to ethically and systematically recruit participants, and to collect and analyse data to explore and describe the factors impacting the return to paid work of individuals following a brain injury (Giorgi, 2000b).

Descriptive and interpretive philosophical tensions and the struggle that arose have been explored. In addition, I have explained how reflection and reflexivity were essential for me to remain true to the descriptive approach, and to explicate the whole rather than interpret the resulting data to allow a deeper meaning of the overall findings to emerge (Finlay and Gough, 2003; Archer, 2010; Finlay, 2011).

The research aims and objectives have been re-evaluated, and a justification provided regarding the final stages of the ongoing descriptive phenomenological journey and how I remained true to the Giorgi descriptive approach (Giorgi, 1997). Chapter five next presents the descriptive participant phase one and two findings, and concludes with presentation of the general situated structure of the overall phenomenon.

Explanation has been provided regarding how the most important components of the phenomenon formed following free imaginative variation, responsive reflective writing and categorial intuition of the descriptive data. The four themes that formed express the essence and meaning of the phenomenon (Van Manen, 1990; Giorgi, 1997; Husserl, 2001; Giorgi, 2006). These four themes are: occupational needs; experiencing loss, grief and adjustment; self-identity; and social inclusion and return to the workplace.

The four themes provide an essence and meaning of the phenomenon whilst staying true to Giorgi's descriptive approach. The four themes, in chapter six, discuss the deeper

meaning and theoretical perspectives of the overall phenomenon in association with synthesised literature and theory and inform and facilitate the development of a return to paid work conceptual framework (Husserl, 2001). The conceptual framework is presented in chapter seven and has directly emerged and been developed from evaluation of the descriptive research findings.

Chapter 5 Findings

5.1 Introduction

Chapter four explained the phenomenological approach that I used to establish the descriptive findings from the phase one and two data. This chapter presents the descriptive findings that emerged. The phase one and two descriptive and emergent findings are presented one after the other. This is following analysis of the research participants' narratives, which reflect both the commonalities and variations between them. Both prevalent and differing findings within the phase one and then phase two emerging themes are reflected in the descriptions of the findings.

Presentation of the phase one findings starts with a selected participant narrative to demonstrate the phenomenological idiographic perspective. This is followed by presentation of the six themes that emerged from the 61 meaning units established from the phase one participant data. Presentation of each of these themes includes both description of the lived experience and participant quotations.

The phase two findings and the further six themes that emerged from the 50 meaning units from the phase two data are then presented. The phase two findings also include a selected participant narrative followed by description of the lived experience and employer quotations.

At the end of this chapter a combined phase one and two story and general situated structure describes the overall phenomenon. These descriptive findings fulfil the research aim and describe the factors impacting return to paid work from both the perspective of individuals following a brain injury and employers in England.

5.2 Phase one findings

The phase one participants who had sustained brain injuries were presented in chapter four, 4.8. Appendix 12 provides a demographic summary of the phase one participant data. Pseudonyms were allocated to each of the phase one participants and are summarised in 5.2.1 below.

5.2.1 Table of phase one participant pseudonyms

Participant	Pseudonym
One	Melvin
Two	Phil
Three	Peter
Four	Chris
Five	Julian
Six	Sarah
Seven	Martin
Eight	Dawn
Nine	Edward
Ten	Gill
Eleven	Dave
Twelve	Carl
Thirteen	Verna
Fourteen	John
Fifteen	Fiona
Sixteen	Sandra

Analysis of all 16 injured individual narratives identified a number of constituents, which reflected both the commonalities and variations between them (Giorgi, 1985; Spinelli, 2005). Both the prevalent and differing findings within the emerging themes are reflected in the following description of the findings and include selected participant quotations.

5.3 The themes established from the phase one data

The following six themes emerged from the 61 meaning units from the phase one participant data. They present and describe the phase one, injured participants return to paid work lived experiences and are presented below, and also individually from 5.3.3 to 5.3.8.

5.3.1 Table of themes established from the phase one data

Coping with ongoing difficulties
Expectation and timing of return to work
Workplace colleague reactions
Things that help
Change and return to work options
Feelings of success

5.3.2 A phase one participant's idiographic portrait

Melvin's portrait below describes his phenomenological idiographic perspective. It also demonstrates how his perspective led into the thematic analysis. This is demonstrated with relevant themes being provided and bolded in brackets where this occurred. Selected quotations from Melvin are used within the portrait and in the presentation of the phase one themes. A more detailed breakdown of Melvin's idiographic portrait is also provided in Appendix 18.

Melvin remembered that from the day that he had his haemorrhage that his line manager was a good link back to his workplace, although at this acute time he was more worried about getting back to good health. He remembered post injury realising that if he needed that he could have a year off work, and that his employer was going to be supportive as he had received positive messages and felt encouraged (**led to the Things that help theme**). Three months before returning to work and nine months post injury occupational health became involved, and offered encouragement and helpful tips. They suggested that he should start meeting colleagues before going back to work in order to get back into seeing them and them seeing him (**led to the Things that help theme**).

As return to work approached occupational health advised that colleague reactions may not be encouraging. They explained that some may not know what to say, and rather than say the wrong thing that they may not say anything. They explained that this may feel like they were ignoring him, and *"that is exactly what happened"*. Some people walked away when Melvin approached, leaving him feeling incredibly hurt, but others were welcoming (**led to the Workplace colleague reactions theme**). An immediate problem was that *"a lot of people had changed as it was a year since leaving work",* and some had moved on. Melvin felt like a *"new boy again".* Melvin had to *"relearn the job"* as he had been out so long, and had forgotten aspects of it. He *"didn't really know what his future role was going to be",* and even he could see that it was going to take a long time to get back. His line manager was helpful, and agreed that Melvin could work half a day each fortnight (**led to the Change and return to work options theme**).

Melvin suffered greatly from fatigue, and felt exhausted just commuting on the train. *"It sounds pathetic but it was just such a huge load being put back on my brain, you know my brain was working ten times as hard as it had been for the previous year"* (**led to the Coping with ongoing difficulties theme**). The Access to Work Scheme completed a

workplace assessment, and Melvin was later provided with voice recognition software and a vertical camera to compensate for residual visual difficulties. His employer also provided a laptop and visual equipment to allow him to work at home. This made him feel that he was going to get back to work quicker, and that a huge commitment had been made to help him (**led to the Things that help theme**).

He returned to work very gradually, four hours (a half day) each fortnight, then two half days each fortnight, then three, four and five. His working day was then lengthened (**led to the Expectation and timing of return to work theme**). His fatigue worsened the more he did. It was 18 months before working full time. His ongoing fatigue, speech and memory difficulties required treatment. Commuting by train over an hour one-way was problematic, *"I just couldn't stand so many people".* Melvin believed this was because he had spent so much time with few people, and never been on his own since his haemorrhage. He thought it was also because he felt that he *"deserved more sympathy, and of course they (the public) didn't care cause they don't know"* (**led to the Coping with ongoing difficulties theme**).

Melvin never thought that he would not return to work, although medical retirement was discussed. He made it clear that he would return to work, was 39 years of age, and did not want to retire (**led to the Expectation and timing of return to work theme**). Colleagues' attitudes towards him hurt, *"they actually saw me coming and they would pick the phone up so I couldn't talk to them. I could see them doing it".* Some senior managers made him feel awkward at times because they had assumed he *"was incapable of doing anything".* Occupational health needed to speak to one of his managers, but the biggest thing for Melvin was every time he had a health set back (four residual operations), he had to start all over again, and by age 51 he believed that he just *"couldn't do it anymore" (***led to the Workplace colleague reactions theme***).*

His return to work was due to his determination and what he *"was before".* This helped as he was getting back his *"sense of the familiar which was comforting because so much had changed".* He craved something that had stayed the same, so returning to work was what he wanted and that he really enjoyed. (**led to the Expectation and timing of return to work theme**). On achieving these personal goals there was a huge sense of achievement; *"the sense of relief when I achieved that as well as of elation of achieving that goal".* He

worked hard but it was something he had to do so he wanted to congratulate himself. *"It felt like I was almost made whole again" (***led to the Feelings of success theme**).

Melvin felt on some days that he had made the wrong decision, but he was driven to go back to work and to be successful. He viewed his job as a big part of who he was. He wanted the recognition of having his job, and the level of seniority was important to him (**led to the Feelings of success theme**). He believes that he would have failed had he not returned to his job, and that *"it would be more stressful going into a job where I had to learn from scratch, and to a team I didn't know".* He needed a sense of the familiar and found that comforting because he had experienced a crisis of confidence from what had happened to him (**led to the Change and return to work options theme**).

5.3.3 Coping with ongoing difficulties

When explaining their lived experiences of returning to paid work all of the phase one participants described becoming aware of, experiencing and having to cope with ongoing difficulties. Their experiences of ongoing difficulties were mostly in relation to one or more of the following: their increasing level of awareness, cognitive ability, fatigue, benefit issues, transport or mental health.

On returning to work, some participants described becoming aware of ongoing difficulties for the first time since their injury, feeling that things were now different, and had changed as experienced by Phil:-

> *"People were really odd with me; they were really strange compared with how they had been before. It was like what is this monster who is here with us, that is what it felt like to me" [Phil].*

The participants described beginning to understand that these difficulties could be related to their brain injury, and how difficult this developing awareness was to cope with. Tasks such as reading and writing at work were more difficult than before, especially when trying to think at the same time. Martin described his experience of this:-

> *"When I got back (to work) I was struggling. I was on the same train but on a different track. I felt really self-aware and that I stuck out like a sore thumb" [Martin].*

The participants experienced new difficulties whilst trying to cope with their developing awareness such as being unable to multitask, unable to cope with noise, and feeling like they would lose their temper. Fiona explained her developing awareness:-

> *"I realised I wasn't right, and I was getting terribly frustrated cause I couldn't understand why I wasn't functioning. All I can remember doing was trying to do things and failing" [Fiona].*

Having to cope with ongoing difficulties was explained by the participants as constantly dealing with setbacks. Despite being very good at work tasks before their injury, suddenly participants described feeling that these were no longer within their grasp, and feeling frustrated. Melvin explained this:-

> *"It was a huge game of snakes and ladders, as I was on a ladder trying to get back up, but because I had so many difficulties, I would slide back down the snake again, and have to start again. I've found that immensely frustrating. There was no other way of dealing with it" [Melvin].*

One of the most prevalent on-going difficulties experienced by the majority of the injured participants when returning to paid work was described as coping with memory difficulties. This presented in different ways such as experiencing difficulty talking to people when unable to remember, getting into trouble for asking too many questions or forgetting instructions and passwords. Memory difficulties were difficult to cope with as described by Carl:-

> *"I struggled for six months to a year to try to make sense of work; I couldn't remember even the simplest of things" [Carl].*

These experiences of trying to work and cope with memory difficulties appeared very challenging. Julian offered an illustration of the impact his memory difficulties have on his ability to work on some occasions during his working day:-

> *"I'd get lost, I'd go wandering off and I used the spray cleaner sometimes instead of the proper spray"[Julian].*

For some participants coping with these difficult experiences left them feeling unsure of work relationships, worthless or led to job loss. Sarah described her experience of this:-

"I often cried and thought I wasn't worth anything. I knew I couldn't cope" [Sarah].

Fatigue was also a significant on going difficulty that the majority of the participants had to cope with. They described constantly feeling exhausted, sleeping for 20 hours each day, and spending most of their time in bed. Melvin described his experience of fatigue:-

"My brain was working ten times as hard…, the fatigue was just unbelievable. I would not have felt that it could have worsened any more but it did" [Melvin].

The participants described really struggling to cope with increasing levels of fatigue at work, not knowing how to manage it, having to take extended time off, feeling angry and tired all the time, and resultant job loss. Phil explained trying to cope with his fatigue:-

"Everything I was trying was making feeling exhausted harder, and I was failing. I knew nothing about it, nobody had told me, and I was panicking thinking where am I going wrong" [Phil].

Melvin, Phil, Peter, Chris, Julian, Martin, Dawn, Edward, Gill, Carl and Verna, all described how tired they became whilst working. Edward's illustration summarises the essence of this, when he described how he became really drained as the day progressed:-

"I was on my feet all day and I was really tired and had no stamina, I found it really draining so I didn't really last" [Edward].

The impact and potency of the fatigue experienced was described as significant, resulting in additional time off work, angry participant reactions, feelings of despair, and job loss as experienced by Martin:-

"I'd get angry when tired or when plans changed. It was real fatigue, a different type of tiredness, I felt ashamed of myself as I felt that I let them (his employer) down because of my fatigue, so I sacked myself" [Martin].

Half of the participants described experiencing difficulties when using the welfare benefits system and felt unable to break free of having benefits. These experiences were described as stressful, resulting in them having no money, and having to survive on extended overdrafts. Dave described feeling petrified on receiving letters about his welfare benefits:-

"The brown letter from hell that comes from the Department of Work and Pensions about benefits, it's quite stressful" [Dave].

Phil also highlighted his experience of finding himself in a benefit trap:-

"The (Benefit) trap is when you get (earn) more on benefits than you would get if you worked. I had been on Incapacity Benefit and I also get Disability Living Allowance because of (my) epilepsy. For years people have said that I am better off on benefits than going to work, it feels like you are in a continuous circle that you can't break out of" [Phil].

Julian, Sarah, Dawn, Edward, Gill, Dave, Carl and John all experienced some form of transport difficulty mainly due to being unable to drive following their injury and being reliant on other forms of transportation. Dawn offered an illustration of this:-

"The taxi would pick me up at 6.45am as I had to be driven to work; I got travel sick so travelling was very hard for me" [Dawn].

Being unable to cope with crowds of people was described as making transport difficulties worse, and resulted in some participants avoiding busy trains, feeling claustrophobic and not wanting to use buses. Melvin described his commuting experience:-

"I can remember that feeling…, I just couldn't stand so many people, I thought where have they all have come from, I found it really unnerving, and felt that I deserved more sympathy, but all of a sudden I am back with thousands of people, not one of which could have given two hoots about me" [Melvin].

Only three participants described experiencing mental health difficulties. Dawn, Edward and Dave described how their mental health difficulties, depression, post-traumatic stress disorder and agoraphobia, affected their ability to attend work. Edward described how he felt:-

"Quite agoraphobic and apart from going to Headway… I felt really self-aware and that I stuck out like a sore thumb, like a bit paranoid really" [Edward].

Additional ongoing difficulties experienced by individual participants were headaches [Edward] and noise intolerance [Melvin, Edward, Gill and Dave]. Individual participants described experiencing slow information processing, having poor writing ability, speech

difficulties and reading problems. Gill summarised the essence of this when she described her experience of her difficulties:-

> *"I found it very difficult, as I had to write reports after I saw clients and normally I would be typing whilst I'm (I was) talking to them but I couldn't process anymore" [Gill].*

Additional divergent and individual ongoing difficulties were described as reduced motivation and insight, relationship issues, a lack of psychological support and repeated experiences of failure and rejection. The most prevalent on-going difficulties experienced by the majority of the participants however, were fatigue and having a poor memory, and for half of the injured participants transport and welfare benefit difficulties.

5.3.4 Expectation and timing of return to work

An expectation and drive to return to work was experienced by the majority of the participants. They described feeling driven to return to work in order to feel a sense of familiar, to get back to what they knew, and to get back to the person they were before their injury. There appeared to be two aspects to their lived experiences. Some participants described expecting and needing to return to something familiar and others a need to feel like they were improving themselves.

Phil describes the first aspect, and his need to get back to where he had been pre injury:-

> *"I originally expected to go back to work cause I just wanted to go back to where I was,…I wanted to go back to my job so I wanted to go back to how it was" [Phil].*

Similarly Melvin described having this same expectation and need to experience something familiar:-

> *"For me it was a determination that I wanted to get back to what I was before, and that was my primary goal to get back to what I did before….., the job helped,… as it was getting back to the sense of the familiar which was comforting cause so much had changed, err I was craving something that had stayed the same" [Melvin].*

Other participants described the second aspect of this experience, and needed and expected to return to work to help them to recover, and to improve them self. This also

appeared to be linked to getting back to who and where they had been pre injury, but also to not being deterred by their injury. Fiona described her experience:-

> "*I was trying to hold onto something of my life and to not let it all go" [Fiona].*

In addition, Verna described her expectation of returning to work more in relation to not being deterred:-

> *"I wanted to go back as I didn't want to be a victim and be a cabbage on the couch and others think oh bless her" [Verna].*

The timing of return to work appeared to be linked to the participants' needs and expectations, and they described working towards the fastest possible return to work in an attempt to return to their pre injury lifestyles, and their sense of self. There appeared to be three factors related to the timing of return to work with some participants returning to work slowly, some too quickly, and for those self-employed experiencing additional pressure.

A slow phased return to work (between one and three years post injury) was experienced by the majority of the participants, and was described as more successful and satisfying. A fast return (between two and eight weeks post injury), for just less than half of the participants, resulted in failure. Melvin, Julian, Sarah, Martin, Dawn, Edward, Dave, Carl, Verna, John and Sandra all described returning to work slowly, with this ranging across them from a four-hour working day every two weeks to working three short days each week. Martin described his experience of this:-

> *"They let me go back to work one to two days a week to see if I could cope with it… I was allowed to come back at my own speed" [Martin].*

A direct barrier experienced was a fast return to work which resulted in failure for Phil, Peter, Chris, Gill and Fiona. Chris described going back to work only two weeks post injury and the extreme consequences and the quick loss of his job on his return:-

> *"I was on full time duties after four weeks and everything just went wrong after that I was demoted. I got kicked out" [Chris].*

Interestingly both Peter and Gill who described failing on returning to work too quickly were both self-employed. This appeared to be a more pressurised experience as Gill explained:-

> *"I didn't really stop work when I was in hospital as they allowed me to keep my phones, and I was dealing with e-mails and texting people. There was no opportunity to not work, as I was self-employed and bills were piling up" [Gill].*

The majority of the participants' expectation, drive and determination to return to work appeared similar, and to link to a need to connect with their pre injury identity and lifestyle. The most prevalent and successful return to work experience described was a slow phased return to work.

5.3.5 Workplace colleague reactions

Melvin, Phil, Sarah, Dawn, Dave and John described experiencing negative colleague reactions towards them on their return to work. They described their colleague reactions as being predominately related to a lack of understanding about their history or brain injury, and colleagues appearing to not know how to react. Dave described his experience:-

> *"Colleagues with no knowledge of brain injury were the most difficult, which although understandable made it very difficult" [Dave].*

Dawn's illustration also summarised the essence of this lack of colleague understanding:-

> *"Some people would look at me and say I can't see anything wrong with you" [Dawn].*

Phil, Chris, Dawn, Gill, John and Fiona also described negative experiences with their line managers and colleagues, but in relation to how their lack of understanding, as explained above, led to a general lack of sympathy as explained by Chris:-

> *"Certain colleagues were unsympathetic by not understanding the problems I had" [Chris].*

This lack of colleague understanding appeared to impact some colleague reactions as experienced by Melvin:-

" I then returned to work…, and some people actually walked away when they saw me coming, and that felt incredibly hurtful, but I again just thought about it and thought ok that's because they can't deal with this" [Melvin].

Julian, Carl, Verna and Sandra described more understanding and supportive colleague reactions where consideration was given to their needs. Sandra explained her experience on returning to work:-

I flourished, it wasn't too taxing and was routine, and I had plenty of support around me. They (her colleagues} were aware of what had happened to me and were very supportive" [Sandra].

For some of the participants this lack of understanding or sympathy they perceived left them feeling uncomfortable with colleagues, and some feeling unwanted. John reported being called lazy and being bullied by his line manager, and Phil and John both described feeling unwanted in their workplace. Melvin, Dave and John described their colleagues' reactions as hurtful, and Dawn, Gill, Dave and John claimed that their colleagues had little tolerance of them. Phil described his experience and how it made him feel:-

" I always thought that there was someone working against me all the time, or it was like as if something went wrong it was always my fault, and things were always thrown back at me, like you're always overreacting, and it was easy to blame me [Phil].

In addition, Sarah and John described working alone a lot more than they wanted. Sarah offered an illustration and her perception of the situation she found herself in:-

"I was left alone a lot, and that was an issue. All of a sudden you are treated like a child, and just because you had a sight issue you didn't have a brain" [Sarah].

A more divergent finding described by Sarah, Dawn and John, but none the less powerful, was their feelings of being socially excluded by colleagues. Dawn explained how hurtful her experience was, and how it felt being excluded:-

"I was sitting facing a wall and they were all behind me in the office. They arranged lots of socials and never once invited me, and Christmas dos, and I was

never invited. They talked about it in front of me. People my age were all invited but not me. I'm pretty sensitive so it was very upsetting" [Dawn].

From this theme it appears that colleague and line manager awareness, knowledge and understanding of brain injury is important as it appears to influence and impact the way they react, and are able to offer return to work support within the workplace.

5.3.6 Things that help

The participants described things that had helped them most when they were returning to work. The experiences they described included practical support that they had received from professionals and services, emotional support from their families, friends, colleagues and line managers, and for one participant the need for him to feel needed.

Phil, Chris, Julian, Sarah, Edward, Gill, Dave, Carl and Melvin described professional support services that had been helpful such as social work, brain injury team rehabilitation, occupational therapy, Headway, occupational health and case and personnel managers. Their experiences of professional support was predominately advisory or to help them reconnect with employers. Phil explained his experience:-

"My occupational therapist did a lot to help and support me, she came into work a few times to see me, and she talked to the managing director a few times to see how I was getting on, and em the social worker was like also looking into my benefits to see what I could do" [Phil].

A practical support service, Access to Work, was described by Melvin, Dawn and Carl as helpful, as it provided them with both workplace assessment, and taxi transport to enable their return to work. Melvin described his experience of this:-

"Occupational health discussed (the) Access to Work scheme. They had like a workplace assessment, and within say the first four to six weeks they had someone come…, for my area and did an assessment. The practical difficulties were all dealt with. Again I felt really supported by work. Access to Work I think paid for 90% of the cost of the equipment" [Melvin].

Family support, both emotional and financial, was described as helpful by Melvin, Peter and Verna. Emotional support from friends and colleagues was also described as helpful. Verna explained her experience of this:-

"I was very supported by my friends in the village, by guides, and with friends, …the support of my husband and the staff at work, but my husband mainly. Em my husband kept me grounded, one of the things I needed help with is I am a busy person and I do need to fill in my diary. He'd see if I was getting tired or if I was a bit edgy, and he made me clear my diary or re think what I was doing, and step back and calm down em to relieve the pressure" [Verna].

Chris, Julian, Martin, Carl and Sandra all described helpful colleague and line manager support. Carl provided an example of the help he experienced:-

"They (his colleagues) made sure I knew where I was going, (did) not give me too many instructions at once. They are understanding and go slow and sometimes even walk me there and then let me get on with my job" [Carl].

The participants expressed how important they felt it was having supportive people working with and around them. Chris described this:-

"My boss is an understanding bloke, and em he just lets anyone get on with the job. He put me in with a lovely lady who I team up with nicely. The people are definitely important" [Chris].

Similarly Julian described his need for, and receipt of helpful colleague support:-

"I needed someone to look after me, and a bloke at work, his son has problems, he helped me back to work. He said he would go with me everywhere I went to start with so I was accompanied, without him I wouldn't be there. The people really helped; if I hadn't had them I couldn't have got back" [Julian].

In addition, Peter, Chris, Julian, Martin and Verna all described helpful and understanding line manager support, and on reflection Sandra shared her perception and experience of this:-

"They (the people she worked with) were aware of what had happened to me, and were very supportive. Where it hasn't worked out the people didn't know my history, the biggest help was people who understood" [Sandra].

Only one participant, Martin, described his need to feel needed as helpful when returning to work:-

"I feel needed there, and potentially I can do different jobs and feel confident. I work with him (a colleague) and now and again he asks me to help him in the workshop to support him. I feel they need me" [Martin].

All of this practical and emotional support was described as helpful, and as facilitating successful return to work.

5.3.7 Change and return to work options

The participants described experiencing the impacts of changes that had taken place in relation to people they had worked with, becoming aware of changes to their way of working, retraining and changes to their job.

Melvin, Chris, Martin and Dawn described feeling more supported when returning to a workplace where pre injury existing relationships existed, and most of the participants described it being better where not too much change had taken place during their absence. Melvin, Sarah, Martin, Dawn, John and Sandra described facing difficulties as their workplace and colleagues had changed considerably in the time that they had been absent as explained by Melvin:-

"The big problem for me was a lot of the people had changed as it was a year on…, and quite a few that I had worked with had changed, (and) moved on. New people had come in, so going back I genuinely felt like the new boy again…., it would be more stressful going into a job where I had to learn from scratch, to a team and people I didn't know…, in a different job or department I think I would have crumbled" [Melvin].

Similarly, Sandra reflected on her experience of people changing within her work place:-

"When I went back the management had changed em, and I felt that if I had the manager I had had before (her injury) they would have worked a lot more with me, but I just wasn't capable of the job" [Sandra].

Two participants described becoming aware of changes to their previous working practice as Peter described:-

"Unfortunately I was letting people down you know, and I'd never done that in my entire working life, so you know I was making promises that I just couldn't keep" [Peter].

Chris blamed being sent for retraining for negatively impacting his relationship, and explained his experience:-

"They tried to retrain me, I had to go to a specialised place way up north,….at the time as I was married and I had to travel all that way by myself, to learn all about the theory, and I couldn't grasp all the new learning. I got an NVQ but the trouble was that they only looked at jobs in that area, so I had to go all the way home, go on the dole, and start all the searching myself looking for jobs, and basically I struggled. It caused real difficulties between me and my wife at the time cause she was a full time worker, it eventually caused us to drift apart and get divorced" [Chris].

Change to pre-existing jobs and work places also impacted the participants such as organisational change, having to be able to drive, and new computer systems being introduced. Sarah described her experience of this:-

"I decided that I can't do this job as it had so changed, and there were also many changes within the company as well em because we moved premises, and there was a lot of reorganisation…, but I couldn't cope. The job wasn't mine anymore. The main reason was not driving, I couldn't drive there anymore" [Sarah].

No established return to paid work route existed for the injured participants interviewed, and they mostly returned to work via different and unique routes. Only Melvin, Peter, Julian, Martin, Dawn, Verna and John returned to their pre injury jobs, and most of them went on to change their jobs, and found new jobs themselves later on the open job market. The different return to paid work routes that the participants took included: Chris using a Council service retraining scheme, Gill having private work retraining, Edward and Dave doing work placements, Fiona via the Shaw Trust charity and Phil through voluntary work. The remaining participants Sarah, Carl and Sandra also found jobs on the open job market themselves. In addition, once the participants had returned to work half of them experienced some form of job restructuring as illustrated by Dawn:-

"I was officially told that my job was at risk and became redundant. I knew I would go and not the others. It was like working in a state of permanent anxiety" [Dawn].

This theme describes the impact that colleague, work place and job changes had on the participants. It also demonstrates that no established return to paid work route existed for these injured participants to return to work, and that the majority of them found themselves jobs on the open market despite the differing and diverse routes being taken. It is also clear that just under half of them experienced job restructuring following their return.

5.3.8 Feelings of success

Experiencing success and feelings associated with experiencing success were described by the participants following their return to work. Their feelings of success appeared to be associated with their recovery, return to work, and return to the person and life that they had before their injury. Melvin summarised the essence of this:-

"Yeh, just the drive to go back and do it, and be successful because I was looking at the job as a big part of who I was, and I think people do recognise, a bit big headed, but I wanted the recognition em for having that job in the city, and that level of seniority, that was important to me perhaps less after the illness, but I think that getting back to doing a large degree of what I did before was important" [Melvin].

Melvin, Edward, Verna, Fiona and Sandra all described feeling good and valued by once again earning their own way once back in paid work. Verna and Fiona summarised their experiences of this:-

"I like having a job so yeh that's what I enjoy about work. Working feels good to earn my own way" [Verna].

"I feel valued, as they could have easily retired me on medical discharge" [Fiona].

In addition, Melvin, Phil and Carl described feeling like they had achieved success, and of being made to feel whole again by being back at work as further illustrated by Melvin:-

"I had (have) a great memory until the day I die of the feeling of goal achieved…, to actually go and be successful…, the sense of relief when I achieved that (return to

work) as well as of elation of achieving that goal. I worked hard but it was something I had to do, (I) felt like I was almost made whole again" [Melvin].

Melvin, Phil, Edward, Carl, Verna, Fiona and Sandra all viewed their return to paid work as a success, and a boost to their self-esteem despite the challenges. Phil and Carl offered illustrations of this:-

> *"It (return to work) has had a positive effect on me. My wife has noticed that I am more positive. Even after work when I'm exhausted it's a positive exhaustion, cause anxiety and depression can drain the energy out of anyone. I feel better in myself working" [Phil].*

> *"It feels great to be able to fix things again, that was part of the biggest satisfaction of my job, to go and see a door hanging off its hinges, and then fix it all up, and see it fixed and working perfectly. I get a big buzz out of that. Being back in work has helped my self-esteem" [Carl].*

Melvin, Phil, Peter, Verna and Sandra linked their feelings of success to their improved insight and self-awareness, and their recovered ability to perceive personal changes in themselves. The factors described as successful by these participants following their return to paid work reinforce that work appears to not only be essential to their health and future feelings of value and self-esteem, but that they appeared to need to be recovering, and to be meaningfully occupied to restore their sense of occupational and pre injury identity.

5.4 Phase two findings

The participants in phase two were employers of individuals who had sustained a brain injury. The phase two employer participants were presented in chapter four, 4.9. Appendix 14 provides a demographic summary of the phase two participant data. Pseudonyms were allocated to each of the phase two participants and are summarised in 5.4.1 below.

5.4.1 Table of phase two participant pseudonyms

Participant	Pseudonym
One	Phoebe
Two	Emily
Three	Elizabeth
Four	Jude
Five	Robert
Six	William
Seven	Ann
Eight	Jenny
Nine	Daniel
Ten	Diane
Eleven	Kevin

Analysis of all of the 11 employer narratives identified a number of constituents, which reflected both the commonalities and variations between them (Giorgi, 1985; Spinelli, 2005). Both the most prevalent and divergent findings within the emerging themes are reflected in the description of the findings and include selected participant quotations.

5.5 The themes established from the phase two data

The following six themes emerged from the 50 meaning units from the phase two data and they present and describe the phase two employer participants return to paid work lived experiences. They are presented below and also individually from 5.5.3 to 5.5.8.

5.5.1 Table of themes established from the phase two data

Supporting employees to cope with loss and adjustment
Providing practical and emotional support to employees
Facing challenges
Learnt insight
Providing rehabilitation
Awareness of on-going employee difficulties

5.5.2 A phase two participant's idiographic portrait

Pheobe's portrait below describes her phenomenological idiographic perspective. It also demonstrates how her perspective led into the thematic analysis. This is demonstrated with relevant themes being provided and bolded in brackets where this occurred. Selected quotations from Pheobe are used within the portrait, and within the presentation of the phase two themes. A more detailed breakdown of Pheobe's idiographic portrait is also provided in Appendix 19.

Pheobe described herself as a middle manager within a large public organisation, and the line manager of Linda, a 50 year old administrator, who suffered a brain haemorrhage. Linda returned to paid work following four and a half months sick leave. Pheobe explained that, during very icy winter conditions, Linda called her to say that she was experiencing vomiting and double vision. Linda had gone to Accident and Emergency, and had been sent home. A few days later Linda visited her General Practitioner as she had deteriorated, and was immediately referred to a specialist regional hospital. It was confirmed that Linda had sustained a brain haemorrhage. Pheobe observed, and also felt great fear and anxiety at the poor management of Linda's early diagnosis, and felt let down by the NHS (**led to the Supporting employees to cope with loss and adjustment theme**).

Pheobe communicated with Linda daily, often by text, when Linda felt well enough (**led to the Providing rehabilitation theme**). Linda told Pheobe that she felt extremely anxious about returning home, and about what was going to happen, and how it would affect her life. Linda felt quite demoralised, and described to Pheobe experiencing a loss of her sense of identity, even at home where she expected to feel comfortable. Linda felt displaced and devalued. Pheobe explained that this was Linda's perception, not one conveyed by friends and relatives. Linda didn't know who she was any more, which made Pheobe feel quite upset to think that Linda may never get over her loss (**led to the Supporting employees to cope with loss and adjustment theme**).

Pheobe observed remote support from Linda's colleagues, as Linda resisted anyone visiting her, so "*nobody saw Linda for approximately two and a half months post discharge*". Pheobe described her work team as "*very close*", but that Linda refused them

visiting her as she described experiencing "*feelings of shame, embarrassment and fear*", and thought that her colleagues would not recognise her (**led to the Supporting employees to cope with loss and adjustment theme**). Pheobe remembered Linda's first trips out as just walking to the end of the road with family, and that it took a long time for her to have a trip out in a vehicle, and months before using public transport (**led to the Providing rehabilitation theme**).

Pheobe described observing Linda being "*absolutely exhausted even just doing the smallest things, and it would vary from day to day*" (**led to the Awareness of on-going employee difficulties theme**). Pheobe described Human Resources (HR) having contact with Linda, and that no pressure was put on her colleague, which was positive as this gentle approach was in parallel with advice from Linda's Consultant (**led to the Providing practical and emotional support to employees theme**). The HR person had experience of dealing with people following a brain injury, and Linda felt a sense of empathy and understanding knowing that, and that her journey could have been different with someone else (**led to the Facing challenges theme**).

Pheobe described a phased return approach, and that Linda felt a sense of control over this process. Linda was consulted at every stage, and understood that it was a two way process, and could slow it down if she wanted. In the end Linda asked to speed it up (**led to the Supporting employees to cope with loss and adjustment theme**). Linda would plan the steps she wanted to achieve each day, and would not tell anyone. Linda confided in Pheobe that she found it easier to manage the disappointment alone rather than sharing it (**led to the Providing rehabilitation theme**). A plan was drawn up for Linda to work three hour blocks, then she gradually built this up and devised her own timetable in conjunction with HR. Some aspects of it needed to be slowed down, but were able to be changed. Linda's negotiations were with occupational health in HR, as opposed to Pheobe, and decisions were relayed to Pheobe and colleagues (**led to the Providing rehabilitation theme**).

Linda tired really quickly, and when this happened she would tell the colleague she was working with, and would go and sit down or take a more background role. Pheobe described that fatigue exhibited as a loss of strength to lift things, or that Linda would start a sentence and not finish it. Linda perceived her voice as slurred; however Pheobe

only saw "*fractional changes*" (**led to the Awareness of on-going employee difficulties theme**).

"*A tiny bit of conflict started*" when people did things differently to the way Linda wanted them. As Linda's confidence grew there were a few instances of tension, and she wanted her role back, and to be in charge of it (**led to the Facing challenges theme**). Over the last two to three weeks of her phased return she wanted to do the job on her own. It was approximately after five months of phased return before Linda worked full time (**led to the Providing rehabilitation theme**). Linda had lost her confidence driving on icy roads, and felt that this type of driving had triggered the haemorrhage, as she couldn't remember banging her head (**led to the Awareness of on-going employee difficulties theme**). Pheobe's approach was to apply no pressure, and for Linda to take as much time as she needed (**led to the Providing practical and emotional support to employees theme**), and she covered Linda's job role when she wasn't there (**led to the Supporting employees to cope with loss and adjustment theme**).

Pheobe described barriers she observed as Linda's self-doubt and Linda seeing her personality as changed, and worrying that her colleagues would not like the new person (**led to the Awareness of on-going employee difficulties theme**). Pheobe never thought that Linda would make it back to full time work. "*I thought she may have threw the towel in and given up*". Pheobe tearfully described that she had observed Linda's return to work as fragile, and there being a lot at risk for Linda, and her experiencing more failure. Pheobe described feeling a real sense of achievement to see Linda get back, and being moved by Linda's courage (**led to the Learnt insight theme**).

5.5.3 Supporting employees to cope with loss and adjustment

The phase two employer participants described experiences of providing support to their injured employees to help them to cope with loss and to adjust on their return to work. The experiences the employers described were predominantly about support they provided in relation to: loss of salary, making adjustments, dealing with employee anxiety and ability to cope, and experiencing difficulties whilst supporting their employees.

Just under half of the employers described that their injured employees had to cope with financial loss and worries due to their extended sick leave and family commitments. This was illustrated by Jude:-

"He (the injured employee) was off sick for a year and was concerned (that) he had a mortgage and three young children" [Jude].

The employers appeared to support their employees to address this first as Jenny explained:-

"You know we had meetings regularly sort of like once a month, we would all meet together at his (her employee's) house. You know, obviously to save him from having too much stress. Those meetings were designed to try and understand what the company policy was on helping people come back (to work). He obviously was very anxious about how it was going to be affecting him financially" [Jenny].

The employers attempted to put support in place to deal with employees' fears, and to make adjustments to support them. The employers also described their employee's early adjustment as observing their injured employee's anxiety about what was going to happen, not knowing who they were any more, and getting over and adjusting to their losses.

Ann, Jenny and Kevin described that their employees had returned to work too early due to the fears described above, and because of their lost confidence and ability to make decisions. Ann summarised the essence of this:-

"He (the injured employee) told me that the hospital told him that he shouldn't be having meetings with me as he wasn't well enough" [Ann].

Provision of employer support varied, but generally involved the employers staying in regular contact and meeting both formally and informally with employees to plan their return to work. Planning to make work adjustments was described by the employers as both supporting their employee, but also managing their previous job and workload. Pheobe explained support of her employee and the essence of this:-

"There was no issue about it (the job) not being covered fully…, and that her (her employee's) contribution required full cover. Not a case of make do and mend, and that everyone else had to work harder whilst she was off sick. That had an impact on her as she knew she didn't need to be apologetic. If she had come back and the pressure to perform and not only letting herself down but also others, (this) would

have been a huge anxiety, even before she started doing anything. That was fundamental to her recovery" [Pheobe].

Employer support to help employees cope was described by them as not putting any pressure on employees, moving forward in small steps, and being responsive and making adjustments. Emily explained her experience of this:-

"At each point where he (her employee) flagged up maybe something as being a problem, we tried to manage it for him in making and supporting reasonable adjustments. There have been flashes of temper, which he (her employee) has come to see me about. He came to see me as he had used bad language as he was so angry he needed to just get it out. I just sat and listened to him having a little rant then he was fine" [Emily].

The employers described supporting their employees to deal with anxiety, and their responses to loss whilst they tried to adjust. This required the employers being reactive to their employee's needs, reassuring and flexible as described by Robert:-

"He (his employee) said that he wasn't feeling very well, was suffering really bad migraines and was stressed. He said he needed a bit of time off, and couldn't come into work. I asked him to self-certify, so he signed himself off for a week. He had the week off, and came back and we sat and we talked (it) through. He came to the decision that it (his job) was too demanding physically for him, and that he was feeling stressed with the job. He suggested that he wanted to hand in his notice, he couldn't maintain that job, and I talked it through and said that maybe we could come up with a solution. So he's now slightly changed his role" [Robert].

Emily, Jude, Robert, William, Ann and Diane explained the importance of an employee accepting their disability and how this, if accepted positively, affected the injured employee's ability to do their job. Conversely however, they believed it would be a barrier to successful return to work if not accepted.

Some employers found it frustrating and difficult to support their employees to cope with loss and to adjust as explained by William:-

"It's a very difficult position to be in, you also feel constrained by the Disability Discrimination Act, and when you start looking into it, all the things that are

supposed to be there to support people on paper are not necessarily there in reality. For example, when this person (William's employee) lost their driving licence and needed to travel here 25 miles each way every day, I suggested that perhaps some help with taxi fares would be appropriate. We got nowhere. In the end he travelled by train, and another member of staff picked him up at the station and drove him to work. This meant that someone who was recovering from a brain injury had an incredibly long day leaving home at six in the morning, getting back at six o'clock at night" [William].

This theme describes the employers' experiences of supporting their employees to cope with post injury loss, and to adjust to and facilitate their return to paid work.

5.5.4 Providing practical and emotional support to employees

Just under half of the employers avoided contact for the first month of their employee's sick leave, and until they knew the extent of the brain injury condition, severity and longer term prognosis. Practical support provided by the employers included arranging return to work planning meetings, creating a single point of contact for employees, encouraging employees to have a sense of control, identifying and making adjustments, and providing more specialist assessment.

Half of the employers described providing their injured employees with remote support before planning to return to work began, and providing six to eight week progress reviews either in the workplace or at the employee's home. This is summarised by Daniel who described the need to create a single point of contact for his employee:-

"I've always found that if too many people are trying to contact the person it leads to confusion for the employee, and they may be asked the same question by me and their direct line manager, so I try to keep that one point of contact for the employee. He (the employee) knew therefore, who to go to, and I knew that I could also approach his line manager, and see how things were going as well, so I think that's one area that worked quite well, especially in those first three to four weeks the line manager sort of owns that relationship, then you need someone who can have a positive relationship with the employee" [Daniel].

The majority of the employers provided early support that ensured phased planning took place at each review meeting. This instilled confidence in the manager, encouraged

employees to have a sense of control, avoided them feeling under pressure, and provided a supportive approach. Pheobe summarised the essence of this:-

> *"Human Resources had contact with Linda (her employee), and made sure no pressure was put on her…, this gentle approach was in parallel with the advice from Linda's consultant" [Pheobe].*

In addition, many of the employers also provided employees with flexible and supportive options including: reducing their hours to reduce stress, support with tasks for example lesson planning, providing progress feedback to support employee confidence and setting ground rules for their colleagues before the employees returned.

Planning meetings identified the need for adjustments to be made as further explained by Pheobe:-

> *"Thinking back there were some adjustments made to pressure points identified; length of break times, especially at lunch, and boundaries being redefined was quite important for her (the employee) and the team, so over lunch before she had constant interruptions and saw it as part of her job, a defined space was made for lunch, and protected her from those interruptions" [Pheobe].*

The need for more practical and specialist support and assessment was also highlighted such as sorting out benefits, or for specialist adapted equipment as described by Jude:-

> *"He was having some visual disturbance, and issues using the display screen equipment. We had an assessment done by an external organisation" [Jude].*

Emotional support provided by employers included them providing early and reassuring contact with employees, ensuring that support was ongoing, identifying specific individuals that could provide support, and strategies to build employee confidence.

Daniel explained his experience and how early contact supported his employee:-

> *"It identified any issues and talking to and reassuring him on a regular basis, either through meetings or just through email or texts just helped support him" [Daniel].*

Pheobe also explained her experience of providing open ended support, and the emotional impact this had on her employee:-

"She was apprehensive about at what point the support would be pulled, but it was never, it was always open ended, and the most overriding feature of watching her reintegration back to work. She was in control and that was great to see" [Pheobe].

The employers also highlighted how supportive it was where specific identified individuals were there to help employees as explained by Elizabeth:-

"I learnt very quickly that he (her employee) knew the people he could talk to, and obviously I became one of those, and there were lots of times where he would just appear at my door…, he was there and needed me. So I learnt to sort of work that one with him, and tried to give him as much time and support as I possibly could" [Elizabeth].

One employer described the need to provide ongoing reassurance to build the confidence of her employee, and explained the essence of this:-

"You know there must have been a big confidence knock, even though from anybody else's perspective you would look at him and think that he was absolutely fine, but there is this underlying, you know he has still got confidence problems, he needs reassurance regularly that he is doing okay, you know, and I try and give that to him" [Jenny].

This theme describes the practical and emotional support provided and experienced by the employers, and shows that despite some divergence in the support provided, that most employers provided planned and flexible options to their injured employees.

5.5.5 Facing challenges

Half of the employers described the biggest challenge they experienced as a lack of information about brain injury, and how to manage ongoing difficulties experienced by their employees. Employers generally had no knowledge of brain injury, and due to patient confidentiality they were unaware of serious issues such as epilepsy. They described feeling unsupported as there was a lack of medical, psychological and psychiatric support, and the only information they had was from a General Practitioner or employee stating that they were fit to work. Ann's illustration summarised her experience of this:-

"I had no idea that it affected his decision making capability, I've never had any involvement with brain injuries or mental health" [Ann].

Both employers Ann and Kevin explained that the Fit note system was supposed to help, but in their experiences the General Practitioner would tick that the employee was fit for work, but offer no suggestions of how to make that happen or how they should offer support.

A lack of knowledge challenged the employers, especially their lack of knowledge about how to help employees deal with changing roles, to manage their medication, and about risks associated with this lack of knowledge. Provision of brain injury knowledge at an early stage, and how to manage the ongoing difficulties would, in the majority of the employers' opinions, seriously impact the success and management of injured employees returning to paid work.

Pheobe, whilst trying to help her employee deal with role changes, explained the challenge she experienced:-

"A tiny bit of conflict started…, when people did things differently to the way Linda (her employee) wanted them. As her confidence grew there were a few instances of tension, and she wanted her role back, and to be in charge of it" [Pheobe].

Emily did not know how to support her employee to manage his medication, and described trying to manage this in relation to his ability to work:-

"His medication was a big factor, and some days he wasn't right and he needed to be sent home, although he wanted to stay due to his work ethic. He had fuzziness in his head. I think he had a reaction to changes in his medication" [Emily].

The employers faced challenges in relation to risks in the workplace due to their lack of knowledge, and this scared them. William's experience summarises the essence of this:-

"The employee involved was in denial, and it was impossible to get a barely adequate medical, psychological or psychiatric report, so we were unaware of the difficulties, and the employee had two seizures in the school, one in front of the class and the other in his office" [William].

Another employer described her struggle to identify safe ways of preparing her employee to return to work, and explained her experience of this:-

> *"So I suggested that one day he should come into the office, even though he was still off sick, come into the office and do his shift, and practice from here and see how he coped with phones going, people talking around him, people maybe talking to him, yeah, and just see how he coped with that. Initially that was, yes that's a good idea, and then afterwards you know occupational health started to have safety concerns. You know we could then be liable for the fact that you know, he's had another episode because he's come in whilst he's off sick" [Jenny].*

Just under half of the employers identified a further challenge to helping injured employees to return to paid work as the inflexibility of the welfare benefits system, and the anxiety it caused their employees. Employees requested that they could not work over a certain amount of hours as it would affect their disability allowances. Employers were required to clarify this, and manage when employees were on disability allowance, as it only allowed them to work reduced hours each week. Diane explained her experience, and the impact of this:-

> *"He (her injured employee) was living on welfare benefits, there was a limit to how much he was allowed to work so for quite a long time he kept within that limit, and so he only worked a few hours a week" [Diane].*

The employers also described having to manage the impact on colleagues following their injured employees returning to work, and the challenge that posed in relation to increasing workloads and resultant stress. Daniel explained his experience of this:-

> *"I know one other colleague has taken on a lot more work that he (the employee) used to do, and if I'm honest she's finding it quite stressful. I've been told by colleagues that yeah, she is finding it quite hard, and her blood pressure has gone up, and I think that might be a consequence of taking on the work" [Daniel] .*

This theme describes that the biggest challenge experienced and facing employers was a lack of information and understanding about brain injury, and how to manage on-going difficulties and resultant challenges.

5.5.6 Learnt insight

Just under half of the employers described insights that they had become more aware of, and had learned following the return to work experience with their employees. Insights from their experiences included them becoming aware of post injury changes to employee personalities, of issues related to the management of colleagues, of a respect they had developed for their injured employee, and of positive employee outcomes reported on successful return to work.

Pheobe explained becoming aware of how her employee's personality had changed, and how that had impacted her employee whilst she came to terms with her situation:-

> *"She (her employee) just felt really embarrassed that she wasn't functioning as I knew her at work, so the usual extremely communicative very good sense of humour and permanent smile on her face was all gone, and she felt ashamed visually, and that she didn't smile anymore, and that she had no sense of humour any more. All of her friends wouldn't want her anymore, and she felt ashamed that we were keeping in touch with her, and that she wasn't her anymore" [Pheobe].*

The employers reflected on how difficult return to work had been for their employees and colleagues, and on reflection they described better insight and understanding of some of the reasons for the difficulties. Kevin described the essence of this:-

> *"People can't really see how difficult it is, and I think that made it more difficult, because how could they possibly know the effort that's being put in to solve problems, to do things differently, when they can't see it. Some colleagues don't understand a lot of the sort of difficulties, that was a factor, but also the brain injured person themselves isn't sure" [Kevin].*

The employers reported realising that their injured employees' colleagues behaved more positively when they were apprised of what was happening, and that colleagues had more goodwill and admiration for the injured employee. Conversely however, they described that this could be a direct barrier to return to work if colleagues were unaware of what was happening. Jude summarised the essence of this:-

"His colleagues were apprised of what was happening and (the) progress he was making. I think when he started back there was admiration for his grit and determination" [Jude].

Jude, Robert, William and Diane described how they had developed respect for their employees having observed how hard they had worked and adapted to working again, despite this not always being appreciated by their wider colleagues. Pheobe reflected on her employee's journey back to work and her achievement:-

"I never thought that she (her employee) would make it back full time. I thought she may have threw the towel in and given up. There seemed to be a lot at risk for her just trying and more failure, so a real sense of achievement to see her get back" [Pheobe].

*A*ll of the employers above described becoming aware of positive outcomes for their employees on returning to work, such as observing their increased confidence, positive sense of wellbeing, sense of pride in what they were doing, and of feeling more valued. Elizabeth offered an illustration of this:-

"I think this person (her employee) is now prouder of what he is doing, he now feels more valued than he did" [Elizabeth].

Robert offered a further example of this:-

"I think the job satisfaction, I think seeing that he (his employee) is making a difference has built his confidence" [Robert].

This theme describes some of the insights developed and learnt by the employers from their experiences. It highlights them becoming aware of employee personality changes, colleague understanding, and positive outcomes involved when employees return to work.

5.5.7 Providing rehabilitation

The employers described their experiences of providing rehabilitation mainly in relation to a phased increase in their employees' working hours, the consequences of increasing working hours too quickly, their experiences of the fit note system, and ongoing considerations they had to consider to provide return to work rehabilitation.

The most prevalent approach experienced by the employers to provide rehabilitation started with early contact as described by the majority of them. For some employees this was by text and for others with monthly meetings. The employers provided this whilst employees were on sick leave, and for some employees information was communicated via relatives in relation to their progress and for others through occupational health to plan their return to paid work.

All of the employers experienced some form of phased increase in working hours for their injured employees. They devised and provided this with minimal information about brain injury. Generally return to work goals were agreed mutually between employers and employees. Jude described her experience of providing rehabilitation:-

> *"The process started with a very gentle rehabilitation programme, which as I recall was an hour for one day a week. So we literally started off with very gentle steps in him (her employee) travelling into work, having lunch, maybe a chat, and he would travel home. We did that for several months before starting to build on his knowledge base and cognitive function in him resuming any sort of meaningful role" [Jude].*

Jenny and Daniel provided mock up work scenarios that were completed at their employee's homes which supported progress without the employee having to work in an office with distractions such as phones and colleagues talking. Jenny summarised the essence of how this approach developed:-

> *"I suggested he could come into the office even though he was off sick and practice to see how he coped with phones going and people talking around him" [Jenny].*

One employer, William, explained his experience and the consequences of his employee increasing his working hours too quickly:-

> *"He (his employee) was off sick, he came back to work, he told me he was fit to come to work, (and) that his doctor had said he was fit to come to work,……..and then came back full time after a year's sick leave,….though we had to remove his management responsibility" [William].*

The employers felt that the fit note system could have informed and supported their provision of rehabilitation more, and explained that it had not helped them. Ann described her experience and her frustration with this:-

> *"Everyone just seems to be missing something because for me that fit note, it's got this massive box on it that says where the doctor can write suggestions about what they (employees) can and can't do and they never ever use it. They're not helping employers because we want to support people, and if they put more information on to enable us to adjust duties and that kind of thing then we can go with it. If they don't write anything on then we, there's nothing for us to go on, but they just don't seem to want to do that, and it's not helping employers, and not helping the employees" [Ann].*

The employers experienced additional specific issues that they had to consider and manage in order to provide ongoing rehabilitation. These were in relation to managing job needs, relationships with colleagues, and monitoring progress of the rehabilitation they were providing. Whilst satisfying the needs of a job the employers had to manage employees' in relation to their changed post injury abilities with minimal information. William described an example, and his experience of this:-

> *"He had forgotten how to present it which was quite a big issue. When you have someone who has been doing these a dozen years, and you end up eventually having to say look you are not presenting properly, it could become an insult" [William].*

Managing injured employees rehabilitation and their relationships with colleagues was also a consideration described by the employers as relevant. Emily explained her on going management and experience of this:-

> *"He has just grown into a different more confident person, but it only takes one person to say the wrong thing and he goes back down, and he will come to see me and have a rant. Sometimes I tell him the person (colleague) isn't necessarily having a go at him, and it's most likely they aren't having a good day themselves, but he can be sensitive" [Emily].*

The employers described monitoring progress of the rehabilitation they provided. This involved them not only managing their employees' job, but also at times protecting the employee, and putting themselves under more pressure. Jenny explained her experience of this and the impact on her:-

> *"So we were finding that he would be you know, logging on and looking at things, oh that was the other thing that I did, I made sure that he was like removed from email distribution lists, knowing that he would be logging on and looking at extra things. Yeah so I put myself under more stress than I ought to, but I think with him I was more, I could think more objectively around it, you know it's all rehabilitation so protecting him" [Jenny].*

This theme describes how the employers provided rehabilitation, the most prevalent approaches experienced by the majority of the employers and the ongoing issues and considerations addressed.

5.5.8 Awareness of on-going employee difficulties

The employers described experiences where they became aware of ongoing employee difficulties, predominately fatigue, poor memory, an inability to drive and for some persistent headaches.

All of the employers described employee fatigue as the most common on going difficulty experienced in the work place, and that it often happened very quickly and varied day to day. In their experience, fatigue presented itself in different ways such as an employee's inability to lift things, altered speech or employees reporting that following work they would sleep 16 hours. Travel to work involving commuting was also reported to worsen employee fatigue. Phoebe explained her experience of fatigue, how it impacted her employee at work, and the impact on others:-

> *"She (her injured employee) felt absolutely exhausted even just doing (the) smallest things, and it would vary from day to day…, she couldn't count on how fatigued she would feel in any one day, and that affected her forward planning in terms of meeting other people, and making a commitment to do something. She could cope with it if it was only herself she was letting down but not others. When she started to pick up more of her roles, and to interact with the public again sometimes she would tire really quickly, and what would happen was the*

colleague she was working with she would just let know, and she would then go and have a sit down or take a more background role. It was quite erratic and hit and miss" [Phoebe].

On experiencing ongoing employee fatigue the employers appeared to struggle to manage it. Jenny explained her experience of this:-

"He goes home after his shifts…, after three hours work and he's had it. I sort of like, you know even though he thinks he can do more hours, I don't know how to get around this extreme tiredness" [Jenny].

The second most commonly experienced ongoing difficulty reported by most of the employers was employees having a poor memory. Again Jenny explained the challenge of understanding and managing this:-

"*Understanding the things that he (her employee) was describing, he felt as if he could remember everything from before (his injury) but anything new he couldn't. You know he just didn't believe that he would you know, be able to remember anything new but could remember everything old" [Jenny].*

Phoebe, Elizabeth, William, Jenny and Daniel also reported becoming aware that their employees were unable to drive following their injury due to post injury epilepsy or surgery. For those that could drive, but chose not to, they had reduced confidence or had developed a fear of driving. Jenny described this as an additional problem that her employee had to face:-

"You know there's been other problems that he's sort of having…, you know he's sort of like been tested for and… been told he can't drive. But you know, he is an extremely fit person…, and doesn't live very far away…,so he can still get here, and walks in and home" [Jenny].

Some employers were aware that employees experienced ongoing headaches, and subsequent effects from them as explained by Robert:-

"I think when he (his employee) gets tired, he tends to get headaches. I think that brings about anxiety, I think he's worried because originally when the brain injury came about it started with severe headaches, so I think what that does is it takes

him back, and he worries that if he pushes himself too much it may lead to further injury" [Robert].

Additional ongoing individual employee difficulties that employers described were reduced vision, poor attention, reduced tolerance, inflexibility, slow mental processing, self-doubt, social withdrawal, limited insight and difficulty writing.

All of the ongoing difficulties reported by the employers were described as being made worse where colleagues did not understand that they were associated with their colleague's brain injury as illustrated by William:-

"There was a period where there was fewer lessons and there was a great deal of (staff) goodwill and support…….but that tends to evaporate if twelve months down the line, the person is perceived not to be doing their job properly" [William].

This theme highlights fatigue as the most common ongoing difficulty that employers had to manage with their employees when returning to paid work. Other ongoing difficulties experienced were memory difficulties, an inability to drive and for some persistent headaches. The employers explained that colleagues had little tolerance of these difficulties especially when they didn't understand them.

5.6 The story and general situated structure of the phenomenon of return to paid work following a brain injury

This story and general situated structure has emerged from the research findings and the combined phase one and two descriptive summaries presented in Appendices 20 and 21. The intention of the research was to explore the phenomenon return to paid work as expressed by the 16 individuals following a brain injury and the 11 employers of individuals following a brain injury. This story and general structure of the phenomenon has emerged following careful analysis of the phase one and two participants' lived experience narratives. It describes and summarises the overall phenomenon of return to paid work experienced by the participants. It does more than quote or summarise one participant's experience, and provides a comparison of each of the participant's idiographic portraits. The story or structure has been prepared to identify the range of the individuals lived experiences and my perceptions. Wertz's (1985) study provided a useful template for presenting the structure in an organised and coherent way. The phenomenon is structured using seven respective emerging themes from across both the phase one and two descriptive findings.

5.6.1 Coping with ongoing difficulties, loss and adjustment

On returning to paid work both injured employees and employers had to manage the same ongoing difficulties of fatigue, poor memory, transport difficulties, and to negotiate the welfare benefits system. Fatigue presented in different ways and was difficult to deal with, despite being the most common difficulty experienced. Transport was an issue, as most individuals were unable to drive post injury, and this was a barrier to work involving travel in addition to commuting making fatigue worse. Post injury welfare benefits varied and followed no set pattern which caused anxiety when injured individuals were vulnerable and had financial worries due to extended sick leave and family commitments. Some injured individuals returned to work quickly as they could not afford to be off, whilst others were paid fully for twelve months sick leave. Coming off of benefits was complex for both injured employees and employers to understand. Some injured individuals returned to work too early due to these worries and because they had lost confidence and some ability to make decisions. Less impacting but additional ongoing difficulties experienced were reduced motivation, relationship issues, and difficulty coping when plans changed, having reduced self-worth and repeated experiences of failure. Some injured individuals also experienced mental health problems and

experienced depression, agoraphobia or post-traumatic stress. They experienced feeling anxious in crowded places and in enclosed environments felt claustrophobic. For some loss influenced early post injury adjustment in relation to feelings of shame and embarrassment, fear of not being recognised, not being able to remember quickly, returning home, how the injury would affect their life, not knowing who they were any more and trying to maintain some feeling of control. Employers felt that it was important for an injured employee to accept their disability, and that this positively affected their ability to do their job, although this may involve accepting a changed job role. Adjustment following a brain injury was felt to be harder where colleagues did not understand that ongoing difficulties experienced were associated with the brain injury.

5.6.2 Expectation and timing of return to work

Individuals following their brain injury expected to return to paid work as soon as they could, and described a drive to get back to their pervious lifestyle. This drive came from them and not others, and enabled them to be able to see themselves as they were before their injury, and as their former self and identity. Employers, despite witnessing injured employees having financial worries, mainly encouraged them not to return to paid work until they were fit. A slow phased return to paid work was more successful and satisfying for both injured individuals and their employers, and a fast return (ranging from four to eight weeks post injury) resulted in a poor experience and failure, especially for those who were self-employed. Consequences of a fast return included injured individuals becoming suddenly aware of memory problems, attention deficits, fatigue, pain, being demoted, facing failure and resulting in loss of their job. Return to paid work ranged from six to 18 months before working full time post injury. Most injured individuals returned to paid work part time hours, initially ranging from a half day per fortnight to gradually building up to working two to three days with break days in between.

5.6.3 Change and return to work options

Most injured individuals faced difficulty as their workplace and colleagues had moved on during sick leave absence (approximately one year) and colleagues changed. Some have difficulty adapting to change such as changed shift patterns, where jobs have become bigger with more pressure and where duties were different. For some coping with change resulted in stress and headaches. Following a return, job restructuring was experienced by some. This included having to reapply for jobs and being unsuccessful to being made

redundant. Injured employees lived in a state of anxiety when restructuring was happening, as they perceived that they would be the first to go and not others. Injured individuals felt that it was better to return to a familiar job, and that this was more likely to succeed than learning to do a new job, as getting to know new colleagues was more difficult. They described having a sense of familiarity as increasing their confidence. Some injured employees lost their job after returning and some experienced medical retirement. This set them back and left them feeling that life was declining despite their efforts. Some tried work retraining and work placements with varying degrees of success. No return to paid work guidelines existed for these injured employees or employers following the brain injury. The injured individuals experienced different return to work paths including finding themselves jobs on the open market, voluntary work, sheltered employment, the Workstep scheme (for people with any type of disability which helps get back into work), work placements and the Shaw trust (a voluntary, charitable organisation). This was despite all injured employees and their employers facing very similar brain injury symptoms to overcome in the workplace.

5.6.4 Workplace colleague reactions and employer support

Workplace colleague reactions were an important factor in return to paid work. Colleague reactions towards injured employees were hurtful, and resulted in some injured employees being left alone a lot, being treated like children and socially excluded. Colleagues had little tolerance and forgot that injured colleagues experienced on-going difficulties. Due to some brain injury difficulties not being visible it was harder for colleagues to understand them, and to accept that they were real. This resulted in some injured individuals feeling unwanted and perceiving a lack of sympathy in the workplace. Employers generally provided remote support before return planning began and six to eight week progress reviews were set up either in the workplace or at an injured employee's home. Employers generally avoided contact for the first month until they had an idea of the severity and the longer-term prognosis. Direct employer support varied and included looking at flexible options to overcome difficulties, reducing working hours to reduce stress, providing support with specific tasks, reducing pressure, providing feedback of progress to support employee confidence, and setting ground rules for colleagues before the return. Colleague and employer support was required for a successful return to paid work, and colleagues behaved more positively when apprised of what was happening and had more goodwill and admiration for the injured employee.

5.6.5 The rehabilitation provided and things that helped

Return to paid work rehabilitation started with early contact for some injured employees by text, some whilst on sick leave by monthly meetings, some via relatives in relation to hospital progress, and some from occupational health to arrange meetings to look at planning their return. Early rehabilitation often started with using public transport, making travel arrangements or via volunteering. Some started with gentle rehabilitation (one hour for one day a week) or started with travelling into work, having lunch and then travelling home. Generally goals were agreed mutually. A very gradual phased increase in hours worked was most common. Line manager support was thought essential by employers to control an employee's workload. Where possible, negotiation with occupational health was considered better by employers than with line managers, and then relayed to the line manager and colleagues. Things that helped included professional help such as social work, council support services, brain injury team rehabilitation, occupational therapy and Headway. This ranged from help with CV preparation to attending interviews. Colleague attributes that were thought helpful and facilitated return to paid work were tolerance, flexibility and a relaxed attitude. Most helpful was where colleagues understood the on-going difficulties that their injured colleagues experienced. Helpful manager attributes were where managers were supportive and thought carefully about the staff that injured employees were placed with.

5.6.6 Employer challenges and learnt insight

The biggest challenge to employers was their lack of knowledge about brain injury, and the potential health and safety issues related to some subsequent brain injury disabilities. Employers felt unsupported due to a lack of medical, psychological and psychiatric support, and the only information they received was from a General Practitioner or employee stating that they were fit to work. The Fit note is aimed to help, but in reality General Practitioners ticked that an employee was fit for work, but offered no suggestion how to enable employers to support this. Employers were challenged to set up very slow phased rehabilitation, and to manage slow stepped goals to enable slow phased return to paid work. This was in addition to them having to manage injured employees colleague reactions, as often despite them being initially supportive they quickly expected employees to do a full job. Colleagues were described as changing their attitudes if they perceived that a job was not being done effectively. Helpful insight in relation to return to work that employers learnt included not applying pressure on injured employees, them

taking as much time as they needed to return, to gradually build up working hours, and that the line manager needed to know the employee and keep in touch with any occupational or medical advice. Some employers developed a respect of injured employees as they observed how hard they had to work to adapt and to be able to work again.

5.6.7 Feelings of success

Individuals following a brain injury viewed their return to paid work as a personal success, and as part of dealing with their disability, as their perception of their job was very much part of who they are. Part of accepting their disability was reaccepting their adjusted sense of identity. Injured individuals felt valued, made whole again, relieved, experienced a positive sense of wellbeing and pride by earning their own way again. They felt better when working and experienced increased self-esteem. Some injured people recognised changes in their self-awareness and recognised that they were not as bright and quick as before their injury, and understood that the difficulties they experienced were due to their disability. Realisation of what they were capable of often helped them to establish that they needed to live their life with a bit more support around them.

5.7 Conclusion

This chapter has presented the phase one and two descriptive research findings. It has described the phenomenon return to paid work following a brain injury using the lived experiences of both individuals following a brain injury and employers of individuals following a brain injury.

Key findings include barriers such as experiencing fatigue and having a poor memory being established regarding return to paid work. These barriers appear more potent than current existing literature, however transport difficulties and negotiating the welfare benefits system have also been described as direct ongoing barriers.

It appears that no return to paid work guidelines currently exist for employees or employers following a brain injury in England. It has also become evident that lack of vocational rehabilitation is a reality. A further barrier identified was employers' lack of knowledge about brain injury, and a lack of support provided to them. Furthermore, despite Fitness for Work, the Government Response, the use of Fit notes appears not to be currently supporting return to paid work of these individuals (DWP, 2013). These

findings have established that employer support and workplace colleague reactions are important during return to paid work, and that the invisibility of some brain injury difficulties is hard for colleagues to understand and accept.

Specific occupational needs of the injured participants have been identified such as their drive to get back to their previous self and lifestyle, and to their former occupational identity. Participants, following their brain injury, appeared to link personal success with their return to paid work, and their perception of their job appeared very much part of who they saw themselves to be. Connections have therefore been established between their self-identity, increased self-esteem, perceived personal success and return to paid work. A slow phased return to paid work appeared to be more successful for both injured individuals and their employers, and fast return resulted in a poorer experience and failure.

Chapter six next provides an explanation of the essence of this phenomenon whilst staying true to Giorgi's descriptive approach (Giorgi, 2000b; Husserl, 2001). Chapter six discusses and explores the deeper meaning and theoretical perspectives of the overall phenomenon. The ensuing discussion uses the four themes that emerged from the overall general situated structure: occupational needs; experiencing loss, grief and adjustment; self-identity; and social inclusion and return to the workplace to explain how my findings relate to and move the literature on, and to help clarify my contribution of new knowledge.

Chapter 6 Discussion

6.1 Chapter introduction

Chapter five presented the research findings in a descriptive manner congruent with descriptive phenomenology, and described the phenomenon return to paid work following a brain injury using the lived experiences of both individuals following a brain injury and employers of individuals following a brain injury.

This chapter explains the essence and meaning of the phenomenon whilst staying true to Giorgi's descriptive approach, and discusses the deeper meaning and theoretical perspectives of the phenomenon (Husserl, 2001). Following final phenomenological analysis, explained in chapter four, this chapter discusses the four themes that emerged (Husserl, 2001). The following themes directly emerged from the descriptive findings and the overall general situated structure, and highlight issues experienced by the participants.

The chapter is split into four emergent and separate themed discussions. The first discusses the theme occupational needs; the second experiencing loss, grief and adjustment; the third self-identity; and the fourth social inclusion and return to the workplace. The ensuing discussion leads to conclusions that will inform future practice, enable recommendations to be generated, and that facilitate the development of a return to paid work conceptual framework.

6.2 Occupational needs

Discussion of this first theme clarifies how the participant findings directly link to occupational theory and connect with the occupational needs of individuals. I recognised three, directly linked, theoretical sub themes key for discussion. These sub themes focus the discussion in relation to the findings and wider literature. The sub themes are: the occupational nature of the participants; experiencing occupational disruption, dysfunction, imbalance and deprivation; and occupational alienation and injustice. I established these sub themes from occupational theory as the participants' demonstrated clear direct links and relationships to the theoretical underpinnings in relation to their lived experiences.

6.2.1 The occupational nature of the participants

This first sub theme discusses three key factors in relation to the injured participants exhibiting an occupational nature: their occupational drive, the meaning of work as an occupation and their experiences of a positive sense of well-being.

6.2.1.1 Occupational drive

The founders of occupational therapy conceptualised occupation as an essential part of human nature which is manifest by active participation in self-maintenance, work, leisure, play and rest (Meyer, 1977). Most of the injured participants described and demonstrated a drive and expectation that pushed them to get back to their previous lifestyle and work which clearly resonates with occupational theoretical literature, and demonstrates the need for individuals to engage in purposeful occupations, including work.

Mee and Sumsion (2001) suggest that purposeful occupation is innate and related to health and survival. This occupational need was identified and endorsed by the participants, despite each of them having a unique approach. The injured participants confirmed possessing a need and drive to be occupied, and by returning to work appeared to be attempting to influence their own health resonating with Reilly (1962) and Tabor Connor *et al. (*2014). They demonstrated possession of an occupational nature which appeared to be related to the use of their work occupations as suggested by Wilcock (1998). It appeared that return to their daily work occupation was a basic need, and that they were driven to return to their previously chosen and environmental occupations, echoing Meyer (1922). It also appeared that they were using their daily occupations to help adapt and survive as suggested by Mee and Sumsion (2001). In

accordance with the beliefs of Meyer (1922), my findings confirm that following their injury, the participants experienced an occupational drive and need to return to work, and this involved them doing something purposeful.

6.2.1.2 The meaning of work as an occupation

Injured and employer participants described a slow phased return to paid work as more successful, and for some a fast return to work was unsuccessful. Participants described being driven by themselves and no one else to return, but it appears that some returned too soon to provide themselves the best opportunity to succeed. It has to be asked therefore, what was driving them to return so quickly in addition to their occupational need and drive? Could it be that work is so valued in our society, and/or that their social connections and societal expectations also impacted upon their feelings of well-being? (Winefield *et al.*, 2002; Randall, 2015).

Both Levack *et al.* (2004) and Tsaousides *et al.* (2009) explained the meaning of work for individuals following a brain injury, and how working can be perceived as indicative of success, but that success in the workplace was associated with factors other than hours worked or pay earned. Participants in the study by Levack *et al.* (2004) identified feelings of productivity as being a success and experiencing a sense of having done something worthwhile. In addition, participants in the Tsaousides *et al.* (2009) study reported that perceptions of their employability related strongly to their quality of life and feelings of increased confidence. Confirming both of these studies work as an occupation included more than financial gain for my participants. The meaning and purpose of work for them involved them needing to be occupationally engaged and to have a choice, even at an early stage in their recovery. They described and experienced this as being able to fix things again, getting a buzz out of seeing things working, and this directly impacted their self-esteem.

James (2011) and Strangleman (2012) believe that work contributes to how individuals view themselves, their sense of belonging and connectedness, sense of competence when performing occupations, and the participants clearly demonstrated a need to feel connected. Elaborating on the findings of Blank *et al. (*2013), work as an occupation linked and provided meaning for my participants by providing a structure, a sense of purpose, valued role and social connections. Work also provided perceived opportunities for them for meaningful occupation, feelings of satisfaction, to build their self-esteem and promote

recovery even at the risk of failure. Wilcock (2007, p.5) believes that occupations which are perceived as "doing, being, becoming and belonging are essential to survival and health". Wilcock's (2007) beliefs directly relate to and connect with the occupation of return to paid work for the participants. They described being driven and needing to return to work to engage and to be (doing) occupations that they valued such as work. They needed to be (being) hopeful, to have some control over their future (becoming), to feel like they connected (belonging) and had a sense of purpose and meaning (Wilcock, 2007). This confirmed understanding needs to inform future practice.

6.2.1.3 Experiencing a positive sense of well-being

The injured participants described their return to paid work as a personal success, as a part of dealing with their disability, and confirmed their perception of their job as a part of who they saw themselves to be. They experienced feeling valued, made whole again, relieved, and described a positive sense of wellbeing and pride by once again earning their own way. Returning to work made them feel better and they experienced increased self-esteem as a result. Kielhofner (1997, p.55) explained that "when individuals participate in productive occupations that they value, that they are provided with satisfaction and further self-perceived enhancement". This was confirmed and echoed by the participants' feelings of success and well-being, and their motivation to engage in the work they valued.

Roberts (2014), when researching the meaning of participation in chosen occupations, identified that not only can selected occupations provide fulfilment, but they can also provide a sense of restoration. The positive sense of well-being experienced by the participants could be explained by how meaningful their return to work was perceived by them. Whilst supporting this view, Power and Hershenson (2003) portray it in a different way. They established, from their 10 traumatic brain injured participants, that they experienced a perceived loss of value as a person, a major blow to their self-concept and a drop in their self-image when they lost their job. My findings elaborate on those of Wilcock (2007) and Lundqvist and Samuelsson (2012), and highlight that it is important for these individuals to take control of their life and to return to work following their injury, as work is perceived by them as a way to feel like they belong, feel valued, and able to contribute to society.

These feelings not only relate to paid work but also to unpaid work and occupations such as volunteering. Black and Living (2004, p.526) established the perceived benefits from volunteering as positive feelings, such as "rewarding, stimulating, fun, worthwhile or satisfying". Participation in occupations has been shown to significantly relate to multiple outcomes such as health, self-esteem, social competence, happiness, and satisfaction with life (Clark *et al.,* 1991). The participants not only experienced an occupational drive and need to return to work, and that work contained personal meaning and purpose for them, but they also experienced feelings of personal satisfaction and a sense of well-being on returning. They described being made whole again as they had taken control and tried to rebuild themselves, their self-concept and self-esteem, and to promote their own health through engaging in their work occupation.

Clark (1997, p.89) explains temporal character as where "occupations are imbued with meaning in relation to one's sense of the past, present and future" and that through temporality an occupational being has a sense of where s/he is going and that s/he is living to realise future possibilities. Resonating with Clark (1997) it was evident from the participant experiences that by reconnecting with meaningful work they were able to not only return to the person they saw themselves to be in the past and currently, but that they were once again self-perceived as able to have some control over their future that they valued as meaningful.

6.2.2 Experiencing occupational disruption, dysfunction, imbalance and deprivation

This second sub theme of the occupational needs theme explores the participants' experiences and links identified with occupational disruption, dysfunction, imbalance and deprivation, and discusses theoretical relationships.

6.2.2.1 Experiencing occupational disruption

Occupational disruption is where individuals are unable to engage in occupations due to injury and/or environmental changes (Whiteford, 2000). Both injured and employer participants described coping with occupational disruption, particularly in relation to post injury ongoing difficulties, the occupational impact of these and resulting adjustments.

Previously established, in chapter two, individuals following a brain injury can experience ongoing fatigue, cognitive problems, behavioural difficulties and psychiatric symptoms, and these can impact return to work. My participants confirmed the most common

ongoing difficulties experienced in order of their potency of impact were fatigue, poor memory, transport and driving and welfare benefit difficulties. Only three of the injured participants experienced mental health difficulties. Resulting occupational disruption of these difficulties led to occupational dysfunction, as explained by Kielhofner (1997), and contributed to a loss of their pre injury roles, capabilities, occupations, habits, relationships and their sense of themselves.

The impacts of subsequent occupational disruptions dominated the injured and employer participant data in relation to post injury performance deficits. McCrimmon and Oddy (2006) and Hooson *et al. (*2013) previously identified that fatigue not only impedes ability to return to work following a brain injury, but also that further research is needed to establish why fatigue can be accentuated by fear, noise, mess and stress. My participants confirmed that fatigue manifest for them in different ways, and that it was difficult to deal with despite being their most common difficulty, and led to job loss for several of them. Although acknowledged in the literature, fatigue is poorly understood in relation to return to work following a brain injury. Belmont *et al. (*2009), Ponsford *et al. (*2012) and Ponsford and Sinclair (2014) claim that currently health care professionals poorly understand fatigue following brain injury, its causes, how to measure it, and that management of it is poorly supported by research evidence. It is now clearer why both participant groups were unaware or unprepared for the level or length of time that fatigue impacted, and why they had no knowledge that fatigue was a resulting symptom of brain injury.

It has previously been reported that difficulty remembering and concentrating can impact return to work following a brain injury, and this was directly confirmed by my findings (Bjorkdahl, 2010; Artman and McMahon, 2013). Despite memory problems frequently reported, the incidence of specific disorders is unknown (Halbauer *et al.,* 2009). Most common reported memory problems following a brain injury are semantic memory (for words or general facts), autobiographical memory (for time and place), working memory (immediate or short term while using the information to perform a task), episodic long-term memory (events linked to a time and place) and prospective memory (remembering to take medication) (Potvin *et al.,* 2011; Armstrong *et al.,* 2012; Johansson and Tornmalm, 2012; Vanderploeg *et al.,* 2014). Erikson *et al.* (2007) researched the lived experience of memory impairment and described the confusing, frightening and chaotic life-world of

their participants following a brain injury. They described that their participants struggled to achieve new habits and felt a loss of control. Interestingly their participants formed opinions of their current abilities based on their past experiences, and it was suggested that individuals who experience a major occupational disruption like this need to re-establish a sense of continuity with their previous lives.

I have established that it is imperative that injured individuals and employers, before return to work, have detailed knowledge about memory dysfunction and the most effective treatment to establish the best approach prior to return to work. Unlike the experiences of most of my participants, this would allow individuals time to cope with subsequent occupational tensions. They would then be able to adjust to challenges to their identity and occupational disruption, and this would allow them to start to re-establish some feelings of control. Elaborating on Wilcock (1991; 1999, p.2), if the participants continued to experience occupational disruption and have their "doing" disrupted, this would result in their "being" being disrupted which is likely to leave them depressed and unable to achieve their potential. This directly linked to my participants, and is evidenced by Edward's experience, where he subsequently lost his job due to fatigue disrupting his ability to work.

6.2.2.2 Experiencing occupational dysfunction

Kielhofner (1997, p.63) explains occupational dysfunction as a "failure or difficulty engaging in healthy patterns of occupation". To be explicit, this is not the experience of an ongoing occupational disruption, for example the impact of a poor memory, but the occupational behaviour associated with or impacted by reduced memory, for example engagement in work. Occupational dysfunctions as explained by Hocking (2000b; 2009)directly link and resulted in the participants being unable to engage in and achieve previously experienced occupational values, roles, habits, sense of competence, sense of self-worth and their continuous sense of self. This was as a consequence of the ongoing difficulties and disruptions they experienced and described above.

Being able to drive influences return to work and significantly relates to employment stability and an increased likelihood of being employed (Kreutzer *et al.,* 2003; Forslund *et al.,* 2013). My findings further identify that a lack of transport can be a barrier to return to work. Post injury driving appears to be one of the most important roles to individuals following injury as it offers independence, access to communities, as well as employment

opportunities. Driving can be viewed as providing not only transportation, but as contributing to roles that prior to injury formed part of an individual's identity and sense of self (Rapport *et al.,* 2008; Liddle *et al.,* 2012). It has previously been shown that being unable to drive post injury is associated with depression, reduced social interaction and a reduction in community participation (Liddle *et al.,* 2011). Further research is needed as it is unclear if depression is caused by the inability to drive or that the inability to drive is a consequence of depression. My findings confirm those of Rapport *et al. (*2008) and Liddle *et al. (*2012) and that following a brain injury individuals are left unsure if they can drive again and that there is a lack of clear information about driving restrictions and return to driving processes. This is further evidence of how occupational dysfunction challenges individuals following a brain injury, their sense of identity, occupational values and disrupts occupational functioning.

Another example is where the participants attempted to return to work and the benefits system negatively impacted their occupational functioning. My findings highlighted that post injury benefits advice and processes varied and followed no set pattern, causing anxiety at a time when injured individuals were vulnerable and had financial worries. In particular when trying to come off of benefits to return to work, the benefit system proved complex for both injured participants and employers to understand. Complicated applications such as Disability Living Allowance and Employment and Support Allowance left them feeling they were different, confused and out of control in relation to managing their finances.

Literature previously identified anxiety, depression, agoraphobia and psychiatric problems as impacting return to work following a brain injury (Franulic *et al.,* 2004; Grauwmeijer *et al.,* 2012; Van der Horn *et al.,* 2013). Only three injured participants described experiencing ongoing mental health symptoms from depression, agoraphobia and post-traumatic stress, and all three described experiencing feelings of reduced self-worth and repeated experiences of failure.

6.2.2.3 Experiencing occupational imbalance

No single definition of occupational balance exists, although it has been defined as a subjective perception, and of having the right amount and variation of occupations in life (Dur *et al.,* 2015). Dimensions of occupational balance include roles and responsibilities, a balance of time spent and use, time pressure and capabilities and challenges (Dur *et al.,*

2015). Prior to their injuries, the participants possessed their unique balance between work, self-care, and leisure occupations, and filled their time with meaningful and purposeful occupations and roles that they valued as described by Meyer (1977) and Evans (1987). They also had their own temporal order of sleep, self-maintenance, work and play occupations, and Kielhofner (1977) believes that an individual's health is related to the balance of these occupations. Occupational balance does not require an equal amount of time spent engaged in occupations, but "a need to engage in proportions that are satisfying and health promoting" dependant on an individual's motivation and skills (Westhorp, 2003, p.99). Prior to injury, the participants would have made daily decisions about what occupations they would carry out, in an order that suited them, and this would have been shaped by them, and contributed to their perception of their quality of life. This resonates with occupational theory, as following their injury each participant's occupations and roles altered and became imbalanced impacting their meaningful fulfilment of prior roles and functioning. The participant, Chris illustrated this when he described losing his job and the huge challenge for him in trying to balance his occupations only four weeks post injury. Christiansen *et al.* (1998) explained a daily biological rhythm as a circadian rhythm, and believes that it affects health and well-being. For occupational balance individuals need to participate in a variety of occupations, and for well-being to be achieved meaningful "doing" occupations have to coexist with "being" pursuits as believed by Wilcock (1999, p.2) and Clouston (2014). From the participant findings I identified that it is a challenge for them to balance their occupations as it is not always possible for them to have a choice.

6.2.2.4 Experiencing occupational deprivation

Occupational deprivation is experienced when the need for meaningful and health promoting occupations are denied (Munoz *et al.,* 2011). The participants described occupational deprivation when they felt under challenged due to their experiences of ongoing difficulties such as fatigue, memory difficulties and the social impact of their mix of disabilities. This resulted in them having a more limited choice of valued occupations to engage in, leaving them feeling occupationally deprived. The benefits system experience described reinforced this leaving Phil feeling occupationally deprived when he was better off on benefits than going to work. This left him feeling in a continuous circle that he couldn't break out of. Confirming the beliefs of Wilcock (1999, p.2) it appears that, following a brain injury, for individuals to achieve well-being and manage their ongoing

difficulties, they need to be occupationally enabled to “be” the person they want to be and want to “become”.

6.2.3 Experiencing occupational alienation and injustice

This third and last sub theme of the occupational needs theme discusses links between the participants and occupational alienation and injustice.

6.2.3.1 Occupational alienation

Occupational alienation has been defined by Wilcock (2006, p.343) “as a sense of isolation, powerlessness, frustration, loss of control, and estrangement from society or self as a result of engagement in occupation that does not satisfy inner needs”. Occupational alienation results when an individual is doing something that they are either continually not engaging with or where they are socially alienated from others. Individuals become occupationally alienated if they feel estranged from themselves because they are unable “to meet basic occupational needs, or use their particular capacities” because of “the way society is” and the demands it makes upon them (Wilcock, 1998, p.342). My findings link with occupational alienation as they confirm that no return to paid work guidelines or pathway existed for the employees, nor employers in England. All injured participants found their own and different ways back to work, and for the majority this was a long, difficult and often unsuccessful, occupationally alienating experience. Diane, one of the employer participants, provided evidence of this when she described how benefit restrictions left her employee feeling powerless, alienated, out of control and unable to return to work. This resulted in her employee feeling frustrated and unable to engage in an occupation that would have satisfied their needs.

6.2.3.2 Occupational injustice

Occupational justice addresses how society, political direction and/or economic structure “make doing possible for individuals and guides the expectations of that society in relation to the cultural expectations of work, roles, and emerging values” (Jakobsen, 2004, p.125; Townsend and Wilcock, 2004). Ineson (2015) believes that in an occupationally just society, all individuals would have access to sufficient physical, social, economic, and cultural resources as well as support to engage in occupations that are necessary and meaningful to them.

Being able to work is of great importance in an industrialised Western society, especially as individuals are often defined through their work. I was able to link my findings with

occupational injustice as barriers to employment were experienced by all participants. This was due to a lack of return to paid work guidelines or societal support, and the current benefits system being complex. This was despite injured participants and most employers wanting return to work. Phil's experience provides evidence of this regarding the benefit trap where he was earning more on benefits than when working. Phil's experience demonstrates that this benefit trap inadvertently excluded him, resulting in occupational injustice. Whalley Hammell (2008, p.62) defined individuals' occupational rights as "the right of all people to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities". My findings highlight that my injured participants had an inequitable opportunity to participate and access appropriate and relevant paid work.

Despite the Department of Work and Pensions (2014b) starting to recognise employment as a tool for building self-worth and enabling individuals to achieve their potential, it appears not to be recognising the occupational needs of individuals following a brain injury sufficiently, nor how to enhance their needs to make return to paid work a reality for them. Until occupational justice is achieved and the occupational needs of individuals following a brain injury recognised, it appears that they will continue to have limited support and guidance to return to work. In addition, this will cost the state more in health needs, benefits and lost taxes than if these individuals were contributing to society and being meaningfully occupied as my participants clearly longed to be.

6.3 Experiencing loss, grief and adjustment

Discussion of this second of the four themes directly links the participants' experiences of loss, grief and adjustment to Kubler-Ross and Kessler's (2005) theory and stages of grief following loss. To explore this in depth I identified four key sub themes to discuss the theoretical links in addition to related research. The four subthemes are experiencing loss and grief, grief responses, adjustment following loss and guidance in relation to acceptance and the focus of adjustment.

6.3.1 Experiencing loss and grief

Waite (2013, p.539) defines loss as "the fact or action of losing something". Loss is often accompanied by feelings of sadness, especially if an individual experiences losing something perceived to them as valuable and/or meaningful. This directly relates to the participants' specific experiences of loss regarding their pre injury roles, capabilities, occupations, relationships and threats to their self-identity. This sub theme discusses participant losses described and the next emergent theme explores separately, and in more depth, their perceived loss of their self-identity.

6.3.1.1 Role loss

My findings highlighted loss of participant worker and driver roles, and their experiences following loss of these roles such as negotiating a complicated benefits system and transport difficulties, which were established as direct barriers to return to work. Loss of roles should not be underestimated as they can be viewed as catastrophic and to changing the lives of these individuals (Morse, 2000). Chris's experience demonstrated this when just four weeks post injury, everything went wrong and he was demoted and lost his job and worker role. McGrath (2004) similarly established that following a brain injury changes in physical and social status can take place, and that this directly impacts an individual's previous roles such as employee or parent, and can impact on previous role fulfilment. Both McGrath (2004) and my participant experiences confirm that the loss of valued roles is a barrier post injury.

6.3.1.2 Loss of capability

The participants experienced loss of pre injury capabilities and described having a poor memory, reduced writing, speech and reading abilities. This was evidenced by Gill's experience of struggling to mentally process whilst report writing and talking to clients at the same time. In addition, the participants worried about how their injuries would affect

them, and as a result of their changed capabilities questioned who they had become and to know who they were. These pre injury capabilities held personal meaning and valued implications to them. Echoed by Kubler-Ross and Kessler (2005) loss of these threatened their pre injury lifestyles.

6.3.1.3 Loss of employment and relationships

Loss of pre injury occupations left the participants experiencing feelings of loss as explained by Kubler-Ross and Kessler (2005). This was especially when they returned to work very quickly (as early as two weeks following injury), and lost their job or had a change in responsibilities as evidenced by Chris above. In addition to when work relationships changed leaving them feeling like they were failing, and having to work alone more than they wanted as experienced by Sarah when treated like a child and being left alone a lot on returning to work.

6.3.1.4 Loss of self-identity

Self-identity is discussed in depth within the next theme. It is important however to state here that whilst experiencing losses discussed above, that at this same time the participants were also trying to maintain some feeling of control, despite experiencing threats to their perceived self-identity.

6.3.1.5 Experiencing grief

Waite (2013, p.400) defines grief as "intense sorrow, especially caused by someone's death, trouble or annoyance". Unfortunately there is a lack of research concerning grief of individuals following brain injury, although Lefebvre and Levert (2006, p.337) have described grief following traumatic brain injury as "a psychological process enabling a person who has experienced loss to reorganise internally". The participants demonstrated direct connections to the theory and stages of grief when they experienced grieving for colleagues that they had worked with prior to injury no longer being there on return to work (Kubler-Ross and Kessler, 2005). They described finding it hard no longer having existing relationships due to changes that had taken place whilst they were on sick leave. John provided evidence of this when describing having to step back a year in his apprenticeship training. This is also confirmed by the findings of Hooson *et al.* (2013) who reported their 10 participants following brain injuries, on re-engaging in occupations, experiencing a grief reaction and finding this time in their recovery difficult and painful. My findings have confirmed that feelings of grief were experienced when injured

participants started to reengage in their pre injury lifestyles and occupations, and it was then that they began to experience threats, differences and changes to their perceived well-being. Grief reactions are likely to be experienced during and following return to work. Melvin's experience demonstrates this when he described colleagues walking away when they saw him coming or picking up the phone to avoid talking to him, and how hurtful this was.

Kubler-Ross and Kessler (2005) have theorised that there is no one response to loss, but that it is likely that most individuals will experience the five stages of grief, albeit at different times. These stages are denial, anger, bargaining, depression and acceptance, and indeed the participants described experiencing a range of these reactions to their losses. William, an employer participant, described experiencing his employee's denial, and how difficult this was to deal with alongside being unable to access medical information. This resulted in William's employee having two epileptic seizures where he worked, one whilst teaching a class and the other in his office. Both experiences highlight the dangers that can result from denial.

The participants' reactions to loss and grief included headaches, feeling stressed, fatigue, depression, anxiety, claustrophobia, agoraphobia and post-traumatic stress. Wortman and Cohen Silver (1989, p.349) have explained that "in our culture when a major loss is experienced, the normal way to react is with intense distress or depression". This was directly echoed by many of the participants, who experienced feelings of sadness and depression and at times, despite their best efforts trying to cope with losses, that they felt like their life was declining and they experienced numerous setbacks. Hewson (1997, p.1129) has explained the range of potential responses to loss as including "emotional states (such as shock, sadness, anger), physical responses (headaches, fatigue), cognitive responses (denial, confusion, rumination) and behavioural responses (social withdrawal, crying)". The participants experienced many of these reactions as their loss held personal and meaningful importance to them, their values and previous perceived lifestyles. In addition, much of the fear and stress they experienced was a reaction to the loss they perceived in relation to endangering their previously experienced well-being, and as Erikson *et al.* (2007) explained this was due to them struggling to achieve new habits and to deal with feelings of losing control.

6.3.2 Grief responses

Morse (2000, p.3) has explained that whilst feeling sadness an individual may be at the same time recognising "the meaning of the loss and that the future has been altered". A common immediate response to loss can be denial. It is unclear if my participants worked through the five stages of Kubler-Ross and Kessler's (2005) stages of grief as they explain them. It is possible however that the participants, who returned to work too quickly and failed, may have not only returned too quickly due to their drive to engage in occupation, but that they may also have been in denial. Evidence of the outcome of an individual's denial, whilst still grieving and trying to return to a previous lifestyle, was experienced and described by William, the employer participant above.

Lefebvre and Levert (2006) believe that denial is used following traumatic brain injury whilst individuals try to confront what has happened to them. They also suggest that continued, long term use of denial can lead to adjustment delays and denial more likely where prognosis is uncertain. My findings established that the participants had minimal understanding of subsequent consequences of their brain injuries, let alone their prognosis, and for them the grieving process was likely prolonged due to this.

Triangulation exists within the literature in relation to the presence of depression and anxiety, and that their presence can predict the likely success of return to work, although to what degree is unclear (Hanlon *et al.*, 2005; Grauwmeijer *et al.*, 2012). For example, McCrimmon and Oddy (2006) found that their unemployed group of individuals following a brain injury reported significantly higher levels of depression than their employed group. Grauwmeijer *et al.* (2012) also reported depression and anxiety as the most common problems of their participants following a brain injury, and Hanlon *et al.* (2005) predicted depression likely to be a key factor in vocational outcome in their research. Not one of my participants received support to help them deal with grief in relation to their loss or resulting grief responses including denial, depression and anxiety that they experienced.

From my findings and this literature it appears that grief and support counselling are required before, during and after return to paid work to facilitate success, especially as denial, depression, anxiety and fatigue can be hidden factors. There is no clear boundary between normal grief and a depressive disorder, as the symptoms of these can appear similar. The assessment of mood disorders following a brain injury remains a challenge. It

is difficult to assess an adjustment mood disorder where individuals are responding to loss to a more serious mood disorder where feelings of worthlessness are experienced (Coetzer, 2006; Hofer *et al.,* 2010). Wortman and Cohen Silver (1989) however suggest that experiencing depression can be therapeutic as it signals that an individual is beginning to face up to their situation, and this was experienced by some of my participants. It is important however those individuals following a brain injury are able to deal with their depression and the required confrontation in order to move onto acceptance and be able to then adjust.

Just under half of the participants experienced job restructuring on returning to paid work. These participants, not only experienced grief as above, but in addition, described feelings of anticipatory grief. They described living in a state of anxiety, especially when job restructuring was taking place in their workplace, when they had to reapply for jobs or experienced the threat of redundancy. Dawn described experiencing anticipatory grief where she was working in a state of permanent anxiety, and felt that she would be made redundant and not others. These feelings of grief accompanied her perception that she would be the first to go, and she described living in a state of anticipatory grief and anxious anticipation. Kubler-Ross and Kessler (2005, p.1) describe anticipatory grief as "a fear of the unknown". Typically this is a grief that people keep to themselves and live in a state of anxiety as described by the participants, and experienced when they had to live with uncertainty and yet more threats to their quality of life. No professional support or advice was available to them at these times.

Factors exist that could influence the judgement of individuals following a brain injury and these need to be considered in relation to potential responses to grief. Yeates *et al.* (2008) researched personality change following acquired brain injury and advised that basic emotions such as fear and anger can be an organic result of cortical damage to the amygdala and sadness following a frontal injury, not as responses to grief itself. In addition, Roundhill *et al.* (2007) explained that individuals following traumatic brain injury, experience reduced insight and cognitive difficulties and may experience more complex responses to loss. Whilst mindful of these factors, it is also important to understand the impact on injured individuals following their personal perceived loss and how their loss affects their sense of self.

6.3.3 Adjustment following loss

Waite (2013, p.11) defines adjustment as “a minor change” and/or “the action of adjusting”. In this sub theme I explore theoretical links regarding how the participants adjusted and made changes following their loss.

Kubler-Ross and Kessler (2005; 2014) have explained that being able to adjust involves individuals reaching the final stage in the stages of grief and being able to accept their loss. Acceptance of loss, in this context, is where an individual is not happy or okay about their loss but is when they accept the reality of it and learn to live with it. Acceptance therefore means that individuals realise that they cannot maintain their past and that they have changed and therefore must adjust (Kubler-Ross and Kessler, 2005). Both participants Martin and Peter’s differing experiences of adjustment provide evidence of this, with Martin’s description of adjusting as realising that he could return to work only two days a week, and for Peter allowing his employer to help by leaving things out for him.

Employer participants experienced injured employee’s adjustments to loss, including their fears and anxieties in relation to what was going to happen to them, and how they could accept their disabilities in relation to returning to work. The employers described that they felt it was important for an injured employee to accept their disability and that this acceptance positively affected their ability to do their job. Conversely, if it was not accepted, in the employers’ opinion, this was seen as a barrier to successful return to work. Both employer and injured participants had to adjust to facilitate return to work, however neither received any support nor guidance to facilitate this. One participant described, that prior to her return to work, she recognised that she wasn’t as quick as before her brain injury as a result of her subsequent disability, and that she had had to realise what she was capable of in order to adjust to having more support around her at work. This was only one participant who acknowledged becoming aware of the need to accept and adjust, out of all of the injured participants, however all of them described struggling with this stage but on their own and for the majority of them in an ad hoc, uninformed manner.

Lundqvist and Samuelsson (2012) claim that it is important for individuals following acquired brain injury to have the ability to change, to take control of their life and to learn to cope with ongoing symptoms. Currently it is not known how these individuals are or

can be enabled to make that change and to cope in order to take control when returning to work. Furthermore, Baldwin *et al.* (2011), on researching why it can be difficult to persuade people with memory difficulties to use strategies, despite their value, found that injured individuals often had to first overcome emotional barriers before memory compensations were used. Little is known about how these individuals are enabled to overcome emotional barriers stopping their ability to accept and adjust. My findings have highlighted that guidance is needed for both individuals following a brain injury and employers in relation to what to expect, and how to best facilitate injured individuals' acceptance and adjustment before and during their return to paid work to best facilitate their return.

6.3.4 Guidance in relation to acceptance and the focus of adjustment

6.3.4.1 Guidance in relation to acceptance and adjustment

Research evidence is next discussed to increase understanding of the acceptance and adjustment of individuals following a brain injury (Chamberlain, 2005; O'Callaghan *et al.*, 2006; Roundhill *et al.*, 2007; Turner *et al.*, 2011). This evidence is discussed with my findings and theory with a view to informing how acceptance and adjustment may be facilitated to prepare for return to work.

Roundhill *et al.* (2007) investigated how seven individuals following a traumatic brain injury accommodated loss. This resulted in four themes emerging: emotion focus, progress focus, issues of control and post-injury growth. The emotion focus explained their gradual acceptance of the reality of their injuries, following a period where they protectively remained unaware, which indeed may have been denial. This progressed to overwhelming feelings, and for some thoughts of suicide on realisation that they were no longer able to cope with overwhelming changes. Although intense, this appeared to represent a turning point and lead to a focus where their participants accepted things. They then tried to take control over difficulties, sensing that they needed to lead change and seeing previous ways of life more negatively and in contrast to the present. This directly connects with experiences of my participants as they described severe depression and grief reactions to their loss, although it was not clear how or when they individually reached their turning points to move on. Perhaps if individuals are unable to move on they are less likely to succeed when returning to work, to take control, accept and adjust, and this could be one reason why they are not successful when returning. They may not

only be returning to work too early, but also when they are still grieving and not able to adjust.

Turner *et al.* (2011) on researching recovery perceptions of 20 individuals following acquired brain injury established four themes: adapting to life, variations in recovery, emotional adjustment rollercoaster and discovering the new me. On adapting to life their participants faced injury related, environmental and relationship obstacles very similar to those of the participants. These obstacles prevented them from doing what they wanted. Variations in recovery included trying to return to driving and work as their participants' most common goals and extreme frustration when unable to achieve this. The emotional adjustment rollercoaster explained disappointment as their participants realised their expectations were not being met and resulted in varying outcomes including depression, becoming withdrawn, aggression and driving against advice. Discovering the new me lasted throughout their recovery journey and included grieving for the person they had been before their injury and learning to understand the new person they had become. It seemed important to these participants to have knowledge of their injury and how it impacted their life to influence their adjustment. Only a small number of them were able to embrace their new life and were reported to have better outcomes. From both my findings and this research there appears a need to better support individuals with information about their injury, the impact of subsequent difficulties, and to help them manage barriers. These findings directly apply to the participants and mirror data collected in relation to adaptation, recovery variations and emotional adjustment. What is less clear on comparison however is how the participants went about discovering their new selves, despite evidence of them grieving for the person they had been. It could be that some of the participants had not been able to understand or connect with the new person they had become, nor obtain knowledge of their injury and its impact on their life and therefore were unable to fully adjust. This would explain why some of the injured participants coped better than others and seemed more aware of how their injury had impacted their life, and this does appear to have influenced how successfully they adjusted.

O'Callaghan *et al.* (2006) explored experiences of gaining awareness of deficits with 10 individuals following traumatic brain injury and established eight themes: learning from reactions, personal discovery, explanations, obstacles to awareness, fear and loss,

avoidance, accepting changes and social stigma. Their participants highlighted the importance of honest feedback from others as helpful, and that they had to experience something, often several times, before realising that something was wrong. They also found injury explanations helped them to understand and feel less stressed. Interestingly they reported the invisibility of their injury as a major difficulty as others assumed that they had completely recovered as they were unable to see difficulties. They tried avoiding and denying difficulties as this allowed them to feel better for a while, but also acknowledged that their denial prevented them from recovering further. Acceptance only began when they started doing something about their difficulties. These findings concur with the journeys and reactions to losses experienced by the participants. From my findings and this research it appears crucial that the participants should have been informed about the invisibility of some of their injuries as they were totally unaware that these were consequences of their brain injury, let alone that others would assume that they had no subsequent difficulties to deal with and expected them to have completely recovered.

Chamberlain (2005) described the experience of 60 surviving traumatic brain injured one year following their injuries. Five themes identified were regret and grief, insensitivity of health professionals, invisibility, feeling stranded and recovery. The moment when injury occurred was a continuous reference point for all of their participants and they separated this into two parts, before and after their injury. Similar regrets and losses were experienced by their participants to my participants resulting in grief for all of them. Loss appeared to be relived constantly by them resulting in never ending experiences of grief being experienced. Health professionals were described as insensitive in relation to invisible symptoms suggesting that their participants were malingering, demonstrating a lack of their understanding. Feeling stranded was explained as when their participants realised that they were on their own and had no support or help. Recovery was facilitated by them adopting a transitional identity as a person, the ability to recognise and grieve for loss and an ability to test reality. Although these participants were only one year post injury, their experiences directly relate to my participants in relation to their experiences of grief and loss.

Interestingly the invisibility of subsequent disabilities is again evident, but this time in relation to health professionals lack of knowledge and experience of brain injury. It

consistently appears in the evidence and my findings that individuals following a brain injury refer to anything (including return to paid work) in relation to before and after their injury, and that this appears to be how they may make reference to and to assess their recovery, as long as they are able to avoid continually reliving the grief of their losses. Guidance is needed to help injured individuals recognise and understand grief in order to recover. Support is also needed to help the avoidance of reliving grief, and potentially to help identify a transitional identity they can be aware of and use whilst they accept and adjust to themselves as an emerging adjusted person.

6.3.4.2 The focus of adjustment

My participants and all of the participants presented above focussed their recovery and adjustment direction towards and based on their past lifestyles, capabilities and identities prior to their injuries (Chamberlain, 2005; O'Callaghan *et al.*, 2006; Roundhill *et al.*, 2007; Turner *et al.*, 2011). They all wanted and were working towards getting back to the life and person they were before their injury, and continually compared everything to their previous lifestyle. By focussing in this direction they are at risk of facing disappointment and grief constantly.

McGrath (2004) believes that it is important for individuals following a brain injury to avoid this negative approach, and that rehabilitation facilitating adjustment needs to change and refocus its emphasis. Injured individuals need to be encouraged to embrace a new lifestyle for themselves, and not constantly be trying to return to their previous lifestyles. It appears important that health care professionals therefore avoid aiming to restore injured individuals to their pre injury status, but set out to enable the development of a newly developed status for the injured individual, with connections between both their past and new statuses. This would avoid injured individuals continually reliving loss and grief, and provide a better and more acceptable means for them to look forward and to adjust.

6.4 Self-identity

Discussion of this third theme explores links between the participants' experiences of return to paid work and their self-identity. I briefly explore symbolic interaction, however Erikson's (1980) life span psychosocial theory is most relevant as identity is the central theme. This theme also shares connections with occupational theory and the theory and stages of grief following loss (Kielhofner, 2002; Kubler-Ross and Kessler, 2005). To explore the underpinning meanings of this theme in depth I established four key theoretical and research driven sub themes to focus the discussion. These four sub themes are experiencing threats and challenges to self-identity, fighting for one's identity, occupational identity and adjusting and facilitating adjustment of self-identity. Prior to discussing the four sub themes, 6.4.1 first summarises life span psychosocial theory, symbolic interaction and self-identity.

6.4.1 Key theories and self-identity

Erikson (1980) believed that by adolescence most individuals' identity has formed from experiences with their parents, and that this identity is a foundation to continue to develop sense of self, feelings of satisfaction, self-esteem and identity (Schwartz *et al.,* 2013). Self-identity is where an individual is aware of the person they believe them self to be and where they realise what is unique about them and makes them different to others (Wilson *et al.,* 2015). Self-identity can be reinforced and changed by the ways others perceive and categorise individuals such as by their age, gender, race and by occupations they engage in, in addition to being influenced by their environment, culture and role modelling (Christiansen, 2000).

Symbolic interaction theories explain that individuals interpret the actions of others during social interactions, and use these interactions to influence views about themselves in relation to what others think about them (Blumer, 1969; Ownsworth, 2014). It is therefore believed that membership of social groups' helps individuals to form self-identity and roles during interactions with others (Hogg and Vaughan, 2005).

Erikson (1980) claims that success during stage five of his eight life stages (Identity versus Confusion) results in individuals' having a unique view of themselves, and it is believed that individuals update their self-identity following experiences, resulting in alterations in their self-identity (Coetzer, 2008; Winegardner, 2015). Following a brain injury, individuals display a grief like response to the fragmentation of their self-identity,

however applying Erikson's (1980) theory suggests that individuals are able to refine their self-identity over time (Persinger, 1993).

6.4.2 Experiencing threats and challenges to self-identity

The participants all struggled to keep control of their lives whilst they grieved their losses, and dealt with threats to their self-identity whilst trying to and during return to paid work. This first subtheme discusses their experiences of threats to their self-identity followed by experiences of the perceived loss of their self-identity.

6.4.2.1 Experiencing a threat to self-identity

It has been established that individuals following a brain injury have to cope with challenges to their identity, and it has been reported that as many as 72% of brain injury survivors report changes to self-identity (Erikson *et al.,* 2007; Bryson-Campbell *et al.,* 2013). These threats to identify appear to influence an individual's sense of self, and indeed resulted for the participants in them experiencing not only feelings of loss but also reduced self-worth and repeated experiences of failure and rejection. Gendreau and de la Sablonniere (2014) confirmed similar findings with their 10 participants, who all explained facing challenges to their self-worth, self-esteem and identity, although only four had suffered traumatic brain injuries and the remainder spinal cord injuries.

Levack *et al.* (2010) synthesised 23 qualitative research studies, and from the 263 participants established that they experienced a mind/body disconnect, disconnect with their pre injury identity, social disconnect and emotional consequences. For their participants this resulted in a changed sense of personal identity and a loss of connection to the person they had been before injury, although some of their participants had suffered mild injuries.

Whilst hard to imagine, this can be further complicated by the ongoing difficulties individuals following a brain injury experience, such as retrograde amnesia and diminished self-awareness, resulting in them being unable to remember subsequent deficits and the impact of those on their lives (Yeates *et al.,* 2008). One's sense of self can be formed from one's internal narratives and memories, therefore a loss of autobiographical memory would remove an individual's personal history and further threaten their self (Pachalska *et al.,* 2011). Coetzer (2008, p.768) explained self-awareness as "a cognitive building block that underpins a person's sense of identity", so

to experience the disconnected feelings experienced by the participants and a subsequent lack of awareness, would not only threaten their identity, but others would experience a change in that individual in the way they presented and this would impact upon their roles and social interactions.

Individuals react differently to threats to identity but humans have a basic drive to better understand themselves, and to reach their full potential. The participants were searching for themselves as they saw themselves before their injury, and it is now understandable why they drove themselves so quickly and hard to return to their previous self and life despite risks of failure. Phil's description of trying to get back to how and who he had been provides an example of this. Consequences of the threats to self-identity following a brain injury have been reported as resulting in changes in emotional connections, such as subsequent anxiety, depression and reports of suicidal ideation as experienced and also confirmed by the participants (McGrath, 2004; Levack *et al.,* 2014).

6.4.2.2 Experiencing a perceived loss of self-identity

It has been established by Soeker *et al.* (2012a) that individuals following a brain injury can experience a sense of loss of their former self, loose self-confidence and feel underestimated by society and no longer sure of whom they are. Employer participants described observing that their employees didn't appear to know who they were anymore, therefore supporting Soeker *et al.*'s (2012a) findings. Power and Hershenson (2003) also reported their participants experiencing a major blow to their self-concept, a drop in self-image, and more importantly that for the participants with a well-developed work ethic, loss of work led to a perceived loss of value as a person. These responses to the perceived loss of self-identity connect with Kubler-Ross and Kessler's (2005) theory of grief following loss as well as Erikson's (1980) life span psychosocial theory.

There is no doubt that individuals following a brain injury can experience "catastrophic changes in the sense of self", and that these changes can range from vague feelings of no longer being the person they were to no longer feeling like a person at all (Persinger, 1993, p.1060; Thomas *et al.,* 2014). Julian's experience of not seeing himself as he previously had been, and his longing to get back to work to try and return to his previous self not only demonstrates this, but also that he was returning to work as quickly as possible to find his identity. These individuals not only grieve the loss of their pre injury roles, capabilities and relationships, but also the perceived loss of their pre injury identity.

This is complex as whilst grieving they also attempt to restore and acknowledge their former identify by returning to engage in their pre injury work occupation, roles and relationships as soon as they can.

This perceived loss of self and identity can leave these individuals feeling overwhelming grief and anxiety, and scared that they may not find their previous self (Wilson *et al.*, 2015). When explaining social disconnect and loss, Levack *et al.* (2010) stated that their findings, following a qualitative synthesis of 23 studies including individuals following traumatic brain injuries, highlighted that these individuals felt abandoned by everyone and everything they knew, and experienced immense feelings of sorrow and loss on losing friends and employment. My findings and the studies discussed have established that this is a vulnerable time for individuals following a brain injury, and that it is important that they are helped to recognise and understand what is happening to them, and that the feelings they experience are part of and consequences of their injury. They need time to grieve for their previous identity, and to understand that resultant feelings of depression and reduced self-esteem may be experienced whilst they are trying to come to terms with their perceived loss, and as found by Carroll and Coetzer's (2011) 29 participants following their traumatic brain injuries, the greater their perceptions of change or loss of identity the lower their levels of self-esteem may be.

6.4.3 Fighting for one's identity

Individuals following a brain injury can view their work as a large part of who they are (Opperman, 2004). Petrella *et al.* (2005) claim that injured individuals need to fight for their identity, and that this means them struggling to maintain their sense of self, which involves pushing their beliefs about themselves based on their past lives. It is now clearer why the participants prioritised return to work as a means to re-establish themselves and to fight for their identity, as they were fighting to find themselves. Carl's experience of being able to fix things again on returning to work and his increased feelings of self-esteem demonstrate evidence of this.

Gendreau and de la Sablonniere (2014, p.1613) explain that injured individuals initially try to preserve their pre injury identity, looking for continuity in their sense of self, and what they term an "identity anchor". This is whilst starting to grieve for their old self, trying to make sense of their new emerging self and attempting to make connections between both. In the previous theme, Chamberlain (2005), following research with 60 participants

following traumatic brain injuries, claimed that their recovery was facilitated by adopting a transitional identity, and that this allowed their participants space to grieve whilst trying to find their new identity. It appears, as explained by Dewar and Gracey (2007, p.603), that injured individuals may possess two self-images "who I was before the injury" and "who I am now", and that this has implications for who "I" might become. This relates to Erikson (1980) but also to the participant Carl's description above. Whilst Carl described being pleased being able to fix things again and feeling good about engaging in his pre injury work occupation and his pre injury identity, he was also engaging with what that meant to him and for his future. Conversely however, realisation of a discrepancy between pre and post injury identities has been associated with anxiety and depression (Bryson-Campbell *et al.,* 2013). Phil's experience provides evidence of trying to fight this where he described needing to fight to work, and that he had realised that, despite work making him feel exhausted, it made him feel less anxious and depressed. He had recognised that anxiety and depression were worse consequences than experiencing what he termed positive exhaustion.

Re-engagement in paid work appears not only to be essential to these individuals' health and feelings of value and self-esteem, but the participant findings established that they needed to be meaningfully occupied to help them restore their sense of pre injury identity, and to potentially help them form their future identity. Their work context offered them the opportunity to fight to redefine their identity, and to satisfy their complex need to return to a previous context where their identity and value was certain. My findings are consistent with the idea expressed by Gendreau and de la Sablonniere (2014, p.1613) of seeking an "identity anchor".

6.4.4 Occupational identity

In this subtheme I explore the relationship between occupation and identity, and occupational identity and brain injury.

6.4.4.1 The relationship between occupation and identity

Hocking (2000b, p.149) claims that "Western people use objects to create and express a sense of self and an identity, and that the way they use objects to achieve this is culturally and historically contextualised". This explains that the occupations that Western individuals select hold personal meaning and satisfaction to them. It also explains that occupations are attached in some way to individual identity, and that participation in

chosen occupations can shape personal identity (Roberts, 2014). Christiansen (1999) first made a connection between occupation and individuals' personal and social identity in the occupational therapy literature. He established that participation in occupation contributes to individuals' construction of their identity, and that it is the primary means for them to communicate this, and indeed this was demonstrated by the participants. Furthermore Christiansen (1999, p.547) believes that "when we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well". This relationship between work as a meaningful occupation and identity explains why the participants were using their work context to not only restore their life meaning and health, but also to help redefine their identity.

Identity is linked to what individuals do and the relationships formed and created whilst doing occupations. Christiansen (1999, p.549) illustrated this connection between doing occupation and identity when reminding us of the question that many people ask each other "what do you do?". Usually this refers to employment with implications of how the working environment may impact identity. This question therefore not only categorises the identities of individuals, but how others reinforce those identities. It has been previously established that occupation is positively linked to well-being, and that it fulfils a basic human need and as a sense of purpose. Being able to understand our self and to reach our full potential is also a basic human drive. Occupation is a means of developing and expressing an individual's identity, so it is now clearer why the participants so badly wanted to return to their work occupation to express their identity.

Wilcock (2007) previously explained the need for humans to be doing (purposeful action), being (living in the moment), becoming (self-actualisation) and belonging (affiliation). Engagement in meaningful occupations can enhance individuals' mood and self-worth, and can be a social interaction which fosters feelings of belonging. Occupations that individuals select (such as their work) are guided by their sense of self in relation to what they value and believe and therefore shape who they become. It is also believed that when there is a threat to individuals being able to engage in selected occupations that it can be perceived as a threat to their identity. This is also known as occupational alienation as previously discussed (Laliberte Rudman, 2002).

6.4.4.2 Occupational identity and brain injury

Occupation and identity are closely inter-related (Kielhofner, 2002; Phelan and Kinsella, 2009). Christiansen (1999) suggested that occupation is the main way that individuals express their identity, and Klinger (2005, p.9) defined occupational identity as "one's sense of and future self, based on one's history as an occupational being". Kielhofner (2002) initiated the term occupational identity, and defined it as "a composite sense of whom one is and wishes to become as an occupational being generated from one's history of occupational participation" (Kielhofner, 2008, p.106). An individual's occupational identity appears to be able to help them to describe who they are, and provide them with some future direction in their lives (Bryson-Campbell *et al.,* 2013). Work as an occupation helps individuals confirm identity to them self and to others, and provides them with feelings of belonging as clearly demonstrated by the participants.

The effect of a brain injury on occupational identity is not well understood (Bryson-Campbell *et al.,* 2013). The impact can be significant however when an individual's occupational identity is fragmented. This was demonstrated by the participant, Melvin's experience of looking at his job as a big part of who he was and explaining how important to him it was that others recognised that, the recognition of having a level of seniority and an important job in London. It was also important to Melvin to get back to his job as he saw it as part of who he was. Melvin not only confirms that his employment was an important part of and connected to his identity, but also that he wanted the recognition of that identity from others, and that it was important for him to return to work to restore his pre injury occupational identity. The participants returned to work to re-establish their pre injury self and occupational identities, and this was related to them trying to restore their abilities and react to threats to their pre injury identity. They viewed return to paid work as a success and a boost to their self-esteem when their occupational identity was restored. More research and understanding of occupational identity could inform strategies to help individuals following a brain injury to occupationally adapt when returning to work and to facilitate restoration or redefinition of their identity.

Christiansen (1999, p.550) believes that occupations contributing to identity are chosen, controlled, and goal-directed, and claimed that "when we create, when we control, when we exercise choice, we are expressing our selfhood and unique identities". By returning to

paid work my participants were trying to control their recovery and to return to and restore their pre injury self and occupational identity. My findings have established that following a brain injury help is needed to recognise how important it is to acknowledge self-identity and occupational identity challenges in relation to the process and timing of return to work to maximise success.

6.4.5 Adjusting and facilitating adjustment of self-identity

6.4.5.1 Adjusting one's identity

It has been suggested that following a brain injury it is important to provide self-efficacy building strategies whilst individuals explore challenges to their sense of self (Power and Hershenson, 2003). Soeker (2011) also provided insight into the process of occupational adaptation in relation to his 10 participants' sense of competency and identity, and how they tried to rebuild themselves by finding contentment with their disabilities and rebuilding their self-esteem. Despite Erikson's (1980) theory suggesting that individuals are able to refine their sense of self and self-identity over time, it is not clear how my participants adjusted their sense of self, and indeed evidence that they did successfully adjust. It could be that they were unable to articulate their identity adjustment as they were unaware that their threatened identity was a factor facing them during their return to work, but only that they struggled returning. They did however describe factors that helped them to adjust during return to work, such as Fiona's experience of feeling valued and the employer Ann's experience of setting up a supportive environment that her employee had the space and time to adjust. They described being in a supportive environment, having the time, feeling valued and acknowledged, and that these factors had helped adjustment, and indeed these need to be included in return to paid work rehabilitation.

6.4.5.2 Guidance to facilitate the adjustment of self-identity

In the absence of further participant findings about self-identity adjustment the remainder of this sub theme explores literature and theory in relation to adjustment of identity following a brain injury. Ownsworth (2014, p.57) describes identity adjustment as "developing awareness of changes (self-awareness), making sense of changes to the self (sense making appraisals) and learning to cope with or manage these (coping and adaptation)". Whilst my participants did not articulate transitions in their self-identity, but mainly threats to it, Ownsworth's (2014) observations are consistent with wider

literature. Two factors that I have established from relevant literature and theory next discuss how to facilitate adjusting self-identity. These two factors are developing an awareness of self-identity changes and feelings of value and belonging.

6.4.5.2.1 Developing an awareness of self-identity changes

It appears important to facilitate increased self-awareness of changes to self-identity following a brain injury. Noonan and D'Cruz's (2007) sample of seven traumatic brain injured individuals explained five themes in relation to their identity adjustment. They firstly expressed the need to discuss and compare who they were before their injury with their current self, that who they were was "completely entwined" with what they did and that changes in their self-identity were linked to changes in their occupational competence (p.158). They also explained that to adapt they needed to accept the new person they had become. This could explain the struggle to return to paid work where self-identity challenges have not been recognised. Currently recognition, redefinition and adjustment of self-identity are not rehabilitation priorities following a brain injury.

Soeker (2011) explained that in order for his 10 participants to adjust that they needed to mentally separate from their previous life and attempt to continue with their life. For my participants it appeared that acceptance of their adjusted sense of identity linked to them accepting their disability and accepting what they were capable of. Available literature appears to confirm this and suggests that part of the adjustment process involves grieving discrepancies from pre to post injury self-identity, and then reconstructing self-identity.

Heller *et al.* (2006) claim that the process of redefining self-identity can take a long time and may take years. This could be why my participants were neither able to recognise nor articulate their adjustment, as it may be that individuals are not aware of self-identity adjustment until it is complete. It may also be that my participants were still struggling with identity confusion, as explained by Erikson's (1980) life span psychosocial theory. Erikson believes identity to be a balance between what he termed identity synthesis (a sense of self over time) and identity confusion (a fragmented sense of the self), so it is plausible that until these individuals successfully rebalanced these that they would not be able to successfully redefine their view of themselves as a person. Erikson (1980) believed that an identity crisis occurs when an individual is unable to establish a stable identity, so it is not only important to help guide individuals post injury to adjust their identity, but

based on this evidence adjustment of self-identity needs to become a rehabilitation priority.

6.4.5.2.2 Feelings of value and belonging

Self-identity can be reinforced by the way others categorise individuals, through relationships, during interactions and through membership in social groups (Christiansen, 2000). It was described as important to my participants that they felt valued in their work and valued by others to be able to adjust. Employer participant Elizabeth's experience illustrated this when she described that her employee appeared prouder of what he was doing, and that he felt valued. Confirming this Levack *et al.*'s (2014) data collected from 49 people following mild to severe traumatic brain injuries, suggested that once they had recovered a satisfying sense of self-identity they needed to be treated like a person of worth by others and by society. My participants described needing to be meaningfully occupied at work whilst being supported, and to feel valued by others in order to help them to restore and refine their sense of self-identity.

Again this links with the beliefs of Wilcock (2007) in relation to humans needing to be doing, being, becoming and belonging (having an affiliation). Engagement in their work fostered my participants' feelings of belonging, and this appeared to be being used by them to help redefine their self-identity. Limited evidence exists in relation to how feelings of value and belonging and return to paid work following a brain injury help to adjust post injury identity. Evidence however does suggest that group membership lends meaning to and strengthens sense of self, helping individuals to see how they can fit in, encouraging them to discuss their losses, and to think about how they have to change to help them accept the person they have become (Gelech and Desjardins, 2010; Jones *et al.*, 2011).

Both Klinger (2005) and Gracey *et al.* (2008) have suggested that a loss of self in the eyes of others and how others see individuals post injury is believed important. This was not directly evident in relation to my participants' self-identities, but could explain why it was so important to them to return to their pre injury self, and does question could this affect their working relationships with others. For adjustment of self-identity to be satisfying following a brain injury it appears that the individual's refined self-identity needs to be valued by them and others.

6.5 Social inclusion and return to the workplace

Discussion of this last theme explores links between the participants, social inclusion and factors impacting return to the workplace. To discuss this theme in depth I recognised seven sub themes as important from my findings, theoretical links and related research. The seven sub themes are: challenges to social inclusion; invisibility, discrimination and stigma in the workplace; the ability to predict return to work success; vocational rehabilitation; sustaining work and both employer and colleague considerations.

6.5.1 Challenges to social inclusion

Inclusionary policy appears to have gathered momentum since Oliver (1983) highlighted inaccessibility of work environments, discriminatory health and social services and negative cultural attitudes towards individuals with disabilities. Social exclusion has been defined as the "process through which individuals or groups are wholly or partially excluded from full participation in the society within which they live" (de Haan, 1998, p.10). Social inclusion is believed important to an individual's health, quality of life and sense of wellbeing. In the United Kingdom, since publication of the Disability Discrimination Act, it is unlawful to discriminate against disabled individuals (DDA, 1995). Despite the Disability Rights Commission trying to ensure that this Act is adhered to, some disabled individuals are still marginalised, excluded from work and socially excluded (Abberley, 2002; Barnes and Mercer, 2005; Davys and Tickle, 2008). The participants confirmed this with their difficult experiences of changing welfare benefits when attempting to return to work and of marginalisation and alienation, all challenging their workplace social inclusion.

The injured participants described feeling unwanted in their workplaces. Blank *et al.* (2013, p.302) researched one individual's experience, who already felt excluded due to mental illness, but on reengaging in work also described feeling excluded and being "deeply aware of the difference and a sense of being separate". Whilst difficult to determine one explanation for these unwanted and separate feelings, it emphasises individuals' desire to feel included and their need to feel a sense of belonging as previously established by Wilcock (2007). The participants described feeling hurt by workplace behaviours, and indeed MacDonald and Leary (2005) successfully demonstrated that reactions to rejection are mediated by aspects of the physical pain system and that social exclusion is experienced as painful. The participants also described

being left alone a lot at work, and interestingly Hawkley *et al.* (2011), on researching how ostracism threatened individuals, found that people experienced reduced feelings of belonging, self-esteem and feelings of sadness, again confirming Wilcock (2007). Hawkley *et al.* (2011) also claim that this pain of ostracism is less intense for older individuals (53 to 71 years) than for younger adults (18 to 53 years). Given the majority of my participants are in the younger age range these findings are relevant.

Belle-Isle and Benoit (2014) looked at social processes leading to social exclusion and identified four dimensions. They identified that relationships with others affect a sense of belonging, a political dimension (where power dynamics influence opportunities to participate), cultural (where norms are either accepted or discriminated against), and economic (where access to resources is influenced by society). In relation to exclusion, Belle-Isle and Benoit's (2014) findings confirm those experienced by my participants, especially where work relationships affected their feelings of belonging. Scott *et al.* (2013), following research looking at the circumstances employees became targets of workplace exclusion, found that employees displaying workplace incivility, such as unfriendly or discourteous behaviours were distrusted and became targets. Scott *et al.* (2013) confirm the cultural aspect of Belle-Isle and Benoit's (2014) findings, where norms are either accepted or discriminated against, and it could be that my participant behaviours may have been perceived by some colleagues as unreliable. Despite the Disability Rights Commission's attempts to ensure that the Disability Discrimination Act is adhered to, my participant findings confirm that they experienced social exclusion on return to their workplaces.

6.5.2 Invisibility, discrimination and stigma in the workplace

The participants described the invisibility of ongoing brain injury difficulties as a major factor on re-entering the workplace, and as contributing to feelings of exclusion. They attributed this to colleagues not understanding or accepting invisible injuries as real and being unable to see anything wrong with them. This concurs with wider research (Levack *et al.*, 2004; Soeker, 2011; Soeker *et al.,* 2012a). Further research also supports these findings, especially related to non-visible cognitive and psychological deficits and returning to work too soon. Gilworth *et al.* (2008) also found that their 33 participants returned to work too soon, not only because they looked ready to return, but due to a lack of advice about how long recovery would take. Both my injured and employer

participants described difficulties knowing how early to start discussing plans to return to work as the injured individuals looked physically well early in the return to work process. In addition, problems with memory, concentration, confidence and planning abilities were all invisible to co-workers, to the extent that co-workers doubted they were genuine (Gilworth *et al.*, 2008). This echoes my participants' experiences, although some participants in the Gilworth *et al.* (2008) study had experienced mild injuries.

McClure (2011) established that public misconceptions occur due to people misattributing the actions of people with traumatic brain injuries. It appears these misattributions have two features: the absence of visible markers of injury and comparisons being made between people with a brain injury and their peers, rather than comparisons being made with individuals' pre and post injury. These misconceptions can lead to discrimination. Furthermore, McClure (2011, p.87) found that the public believed that recovery from a brain injury depends on the injured person's efforts, and that "a person with even a severe brain injury may completely recover". This is very relevant to the participant findings as the majority of them experienced ongoing fatigue (an invisible difficulty). Given these misconceptions, at worst fatigue could be viewed as laziness, and if not recognised as a disability would be less likely to be accommodated by employers and colleagues, could potentially generate discriminatory feelings leading to social exclusion, and as previously highlighted by Scott *et al.* (2013) affect workplace trust.

Ralph and Derbyshire (2013) researched public views about brain injury and confirmed similar factors to those identified by my participants, Gilworth *et al.* (2008) and McClure (2011). Ralph and Derbyshire (2013, p.1483-1484) established that the public expect only "some form of physical impairment" after a brain injury, and that they had a very poor and inaccurate knowledge of memory difficulties. Furthermore, the public believed that the speed of recovery from an acquired brain injury depended on the injured person's efforts, that a complete recovery was likely and that injured people were perceived as less sociable, polite and "not normal". These misconceptions could result in the public perceiving individuals following a brain injury as lazy and even deserving of their difficulties, if it was believed they had not made sufficient efforts to recover. Now that I understand difficulties facing colleagues and employers regarding invisible brain injury difficulties and recovery misconceptions, it is clearer why they may think that these are

not legitimate. It is also clearer why they would expect the same work performance as other employees, and be more likely to socially exclude these individuals.

In 2004 amendments to the Disability Discrimination Act established four types of discrimination: direct discrimination, failure to make reasonable adjustments, disability related discrimination and victimisation (DDA, 1995; Ross, 2007). The participants' experienced a lack of sympathy and tolerance in the workplace consistent with these public misconceptions, and could have led to them experiencing direct and disability related discrimination. There appears to be no research exploring brain injury employment discrimination in the United Kingdom; however McMahon *et al.* (2005) compared employment discrimination experiences of Americans with traumatic brain injuries to those with other physical, sensory, and neurological impairments and identified 328,738 allegations of discrimination, thus confirming its existence elsewhere.

Research regarding stigma and how this impacts brain injury is also lacking, although it has been claimed that if an individual perceives discriminatory behaviour towards an individual following a brain injury as acceptable, and if they expect society to perceive this as acceptable, they are more likely to engage in discriminatory behaviours (Ralph and Derbyshire, 2013; Sabello, 2014). Following a traumatic brain injury, a single case study blamed her poor work performance on societal and employers prejudice and discrimination, explaining this was present especially where invisible symptoms such as psychosocial and cognitive impairments existed (Sabello, 2014). Although only one individual's experience, this also confirms my participant findings. The invisibility and lack of understanding of the participants' ongoing difficulties contributed to discriminatory feelings and challenges to their social inclusion.

6.5.3 The ability to predict return to work success

Not one of the participants received advice to facilitate return or information in relation to predicting their return to paid work. Limited predictions can be made in relation to successful return to paid work. Factors such as injury severity, age, gender, presence of low mood, behavioural problems and to a more limited degree the presence of fatigue and ability to drive have all been identified as negatively impacting return (Power and Hershenson, 2003; Franulic *et al.*, 2004; Van der Horn *et al.*, 2013). These factors whilst attempting to predict the likely success of return to work are currently limited and unclear in relation to their degree of impact.

Synthesis of further researched predictions is difficult due to differing methodologies and injury variables, however increased age, severity of injury and a lack of self-awareness are the most common factors established as negatively affecting return (Keyser-Marcus *et al.*, 2002; Shames *et al.*, 2007). Additional factors such as a history of substance abuse, premorbid occupation, being unable to engage in activities demanding cognition and interpersonal skills have also been reported to negatively impact return to work, but to promote social inclusion in the workplace more detailed research regarding their degree of impact is required to be able to more reliably predict successful return (Ownsworth and McKenna, 2004; Sveen *et al.*, 2008). In addition, further research is needed regarding individuals' psychosocial adjustment and coping skills, and how this impacts predictions (Mateer and Sira, 2006).

6.5.4 Vocational rehabilitation

Only two of the 27 injured participants were described as engaging in recognised vocational rehabilitation, and all others had to manage their own rehabilitation and return to work. This confirms Tyerman's (2012) systematic review findings, where he reported that following a traumatic brain injury in the United Kingdom around 40% of people return to work, but that only a small number of them receive vocational rehabilitation to facilitate this. This limited vocational rehabilitation in itself socially excludes these individuals from return to work.

Both injured and employer participants described barriers such as fatigue, poor memory and an inability to drive as most problematic. Unfortunately little research exists regarding specific vocational strategies, and although evidence suggests vocational rehabilitation may increase return to work rates, "it is neither robust nor overwhelming" (Phillips and Radford, 2014, p.14). There is however some support to suggest that individuals' involvement with vocational rehabilitation may be an indicator of employment outcome (Ownsworth and McKenna, 2004).

Despite a lack of availability and evidence of effectiveness, vocational rehabilitation is recommended to facilitate return to work following a brain injury. Fadyl and McPherson (2009) identified the three most common approaches underpinning vocational rehabilitation as programme based, supported employment and case coordinated. On review of the literature regarding vocational rehabilitation models after traumatic brain injury and their outcomes, four examples exist: brain injury rehabilitation programmes

with added vocational rehabilitation elements, vocational rehabilitation models adapted for traumatic brain injury, case coordination/resource facilitation models, and consumer-directed models (Tyerman, 2012). Unfortunately due to methodological variation the best model cannot be established, nor evidence of efficacy comparisons made, so limited guidance exists and requires further research.

It is difficult to not only question current vocational rehabilitation strategies and their efficacy, but it also appears necessary to reconsider the professional decline in Romanticism and dominance of Rationalism previously explained in 2.4.1 and the dominance of functional and capacity assessment explained in 2.5 (Hocking, 2008c). The emergent needs of the participants relate more to "doing, being, becoming and belonging" which have emerged as requiring a more Romantic than Rational approach, and this suggests that a shift or change of rehabilitation perspective may be required (Wilcock, 1999, p.2). Interestingly in support of this, current evidence suggests that pre vocational training, such as basic work skills (Rational/functional) is less effective than supported employment and research suggests using a supported employment model to be more effective (Holzberg, 2001; Ross, 2007).

Two final elements within vocational rehabilitation research worthy of mentioning are a metacognitive contextual approach and in vivo work training. Metacognition refers to improving self-awareness of post injury changes and an individual's capacity to self-monitor their behaviour. Although some support has been established for this it requires further research (Ownsworth, 2010). Johnson (1998) researched 64 people, 10 years after very severe head injuries and established that 42% had re-established themselves in employment showing in vivo training at work as essential in helping them back to work. Similarly several of my participants used in work/in vivo practice to help them to successfully cope with workplace telephones and noise, so anecdotally they and their employers similarly adopted this approach.

6.5.5 Sustaining work

Consistent with Soeker's (2011) 33 participants, my participants described facing sustaining work with no support, advice or information. There is little research in relation to sustaining work following a brain injury, although Fraser *et al.* (2006) and Macaden *et al.* (2010) offer limited guidance but confirm support for accessing available vocational rehabilitation, ongoing workplace support and increasing self-awareness and insight.

Evidence suggests that work is good for health and wellbeing, but for my participants the beneficial effects of work must have been influenced by the challenges to social inclusion that they described (Waddell and Burton, 2006; Strangleman, 2012). Indeed this could explain the high level of job restructuring they faced and loss of jobs, although interestingly their drive to stay in work appeared to outweigh the social inclusion challenges they faced. It has previously been established that conflict at work can lead to depressive symptoms and that job satisfaction is strongly associated with depression and anxiety (Faragher *et al.,* 2005; Meier *et al.*, 2014). For social inclusion to be ongoing it appears important to help individuals following their brain injury to recognise their difficulties and to be able to access appropriate support. Sustaining work following a brain injury however requires more research especially in relation to how these individuals cope with ongoing challenges to their social inclusion.

6.5.6 Employer considerations

The participant findings explained employer support as crucial for successful return to paid work. Little research exists regarding the attitudes of employers in relation to brain injury and return to work. It has been established however that those following a brain injury who return to work before they are ready, experience greater difficulty adjusting, and that this impacts employers (Ownsworth and McKenna, 2004). Indeed on review of Belle-Isle and Benoit's (2014) research it was established that work relationships affect an individual's sense of belonging and that a lack of access to information affects employer behaviour. Either of these social processes could lead to social exclusion. This employer sub theme discusses two factors experienced by my participants: supportive employer behaviour and negative behaviour and challenges facing employers.

6.5.6.1 Supportive employer behaviour

The participants described the most effective employer support as when employers allowed them time for a gradual return to work, and where no pressure was applied. Macaden *et al.* (2010) found that employers with personal experience of disability were most helpful and this was also confirmed by one of the injured participants. Bootes and Chapparo (2010) highlighted the supportive effect of an employer having detailed knowledge of an employee both pre and post injury, and how this enabled the employer to supportively manage the work situation and help the employee to adjust. This suggests that new employers may be unable to make this pre and post injury comparison, and be

less able to be supportive, thus acknowledging that return to a pre-existing job may be more supportive for both the employer and employees and foster easier social inclusion. This echoes employer participant comments of feeling respect for how hard their injured employees had worked to adapt once back at work.

6.5.6.2 Negative behaviour and challenges facing employers

Employers' lack of sympathy and bullying was experienced by some of the injured participants. This could be explained by the invisibility of brain injury difficulties discussed previously and employers' lack of knowledge of them, with resultant exclusion tendencies as explained by Belle-Isle and Benoit (2014). Sale *et al.* (1991) confirmed similar factors in relation to interpersonal relationships, where injured individuals were unable to cognitively process and verbalise their thoughts, resulting in uncomfortable social situations arising with employers. Specific difficulties reading social cues, such as standing too close to employers led to uncomfortable feelings (Sale *et al.*, 1991). If employers do not understand invisible resultant social behaviours following a brain injury they are more likely to react negatively and be less inclusive.

The biggest challenge described by employer participants was their lack of knowledge and support about brain injury, the recovery process and their fear of not having this information in relation to workplace health and safety. It is therefore no surprise that employers have difficulty creating inclusive workplaces with this lack of information. Despite employers being willing to employ individuals following a brain injury, as established by Rudstam *et al.* (2012), they often do not due to a lack of understanding them, a fear of not being able to accommodate them, and an assumption that they would cost more to employ. This further reinforces how a lack of knowledge is driving employer beliefs and behaviours. Van Velzen *et al.* (2011), following researching factors experienced by 12 adults with moderate to severe acquired brain injuries during return to work, found the most common limiting factor was tiredness (an invisible difficulty). More interestingly however they also found other common facilitating factors as the knowledge and support of the employer and colleagues, and that for return to work to be successful and inclusive employers need to be better informed and supported.

6.5.7 Colleague considerations

The participant findings demonstrated that colleague support is also needed for a successful return to work. This is confirmed by Bonneterre *et al.* (2013) who also found, in their retrospective study of 100 individuals following a traumatic brain injury, that workplace support is a key requirement for job retention. Previously discussed factors relating to invisibility and misconceptions about brain injury also apply to colleagues (Gilworth *et al.*, 2008; McClure, 2011). Following mild brain injury research, Dodson (2010, p.450), described similar colleague reactions such as "you seem fine to me" and "you're lucky to not have any problems from your accident". These early social interactions, yet again set up social conflict where colleagues genuinely believe that the person has made a good recovery and will be as they were before or as capable as their peers. The degree of colleagues' acknowledgement and acceptance of a brain injury impacts how inclusive they appear to be in the workplace. My findings and related research have established that workplace adjustment is harder when colleagues do not understand brain injury and the invisible difficulties associated with it.

6.6 Chapter conclusion

The participants demonstrated an occupational nature, a drive and occupational need to return to work, so much so that they were returning often too soon to afford a successful outcome. Return to work provided them access to purposeful and meaningful occupation, feelings of satisfaction, self-esteem, and promoted their recovery even at the risk of failure. They needed to be occupationally engaged at an early stage of their recovery and to be doing occupations that they valued, had some control over, made them feel like they belonged and had a sense of connectedness, purpose and meaning. Work included more than financial gain, and was perceived by them as a way of getting back to the person they had been, made them feel like they belonged, were valued again, able to contribute to society and they experienced increased self-esteem as a result of returning.

Occupational disruptive barriers included resultant fatigue, poor memory, transport and benefit difficulties, and ongoing occupational disruptions contributed to a loss of pre injury roles, capabilities, occupations, habits, relationships and injured participants' sense of themselves. Barriers such as fatigue, memory problems, driving restrictions and changing welfare benefits are poorly understood and require further research. Individuals following a brain injury and their employers require further knowledge about resultant occupational disruptive barriers and dysfunction and advice to help them to balance, restructure and reengage in productive occupations.

Occupational alienation and injustice were experienced by the participants as no return to paid work guidelines existed for them and all injured participants had to find their own and different ways back to work. Currently there appears an inequitable opportunity for these individuals to participate and access appropriate return to paid work support.

Invisibility of subsequent difficulties following injuries is a major barrier and people, including some health professionals, assume a complete recovery has been made. Employers and colleagues would benefit from being informed about the invisibility of injuries, and this could combat some social stigma.

Guidance is required to help injured individuals to acknowledge, recognise and understand subsequent grief in order to support them to help avoid reliving grief, and recovery can be facilitated by the adoption of a transitional identity. Injured individuals continually compare everything to their previous lifestyle putting them at risk of

disappointment and grief. Rehabilitation needs to focus them to embrace their new lifestyle, not to return to their previous one. Health care professionals need to enable the development of a new status for injured individuals and make connections between both their past and new statuses. Rehabilitation needs to inform about injuries, consequences and impacts to expect and the need to focus on adjusting to be a new person post injury. The relationship between when and how acceptance and adjustment are achieved requires further investigation.

The participants experienced threats, challenges to and a perceived loss of their pre injury self-identities, and none of them recognised that this was part of or as a consequence of their brain injury They possessed a drive to return to their previous self and life at a time they were grieving the loss of and threats to their pre injury roles, capabilities, occupations and relationships. They searched for and fought to attain their previous identity to maintain their sense of self, and used return to work to restore a sense of pre injury identity and to form a new identity. My findings established that this is a vulnerable time for individuals following a brain injury, and it is important that they are helped to recognise and understand what is happening to them.

The impact of a brain injury on occupational identity is not well understood, however the participants returned to work to re-establish their pre injury occupational identities and to recover from threats to their pre injury identity. Return to paid work success and restored occupational identity boosted their self-esteem. It is crucial to allow these individuals to mourn their lost self, to recognise and explore distinctions between their pre and post injury selves, and to be able to reconstruct their self-identity. Redefining self-identity is a struggle, may take years and may never be achieved. Group membership and acknowledgement of others lends meaning to and strengthens individuals' sense of self and belonging, and for reconstruction of self-identity to be satisfying an individual's refined self-identity needs to be valued.

The participants experienced social exclusion on return to their workplace. Invisibility of some consequences following a brain injury is a major factor on re-entering the workplace. Ongoing problems with memory, concentration, confidence, planning abilities and mood are all invisible to colleagues and may be doubted as genuine.

Only two of the 27 injured participants engaged in recognised vocational rehabilitation, and a minority of people in the United Kingdom receive vocational rehabilitation to facilitate return to work. The best approach to vocational rehabilitation is difficult to assess so limited guidance exists regarding how to identify the best options. Robust research evidence is needed regarding the effectiveness of vocational rehabilitation.

Employers' lack of knowledge of ongoing brain injury difficulties and the recovery process appears to be driving discriminatory and exclusion tendencies. For return to paid work to be successful and inclusive employers need to be better informed and supported about brain injured people in the workplace.

Colleague support is a requirement for successful return to paid work. Workplace adjustment following a brain injury is harder where colleagues do not understand that ongoing, often invisible difficulties are associated with brain injury. Social inclusion will only be facilitated on return to the workplace when the social processes of increasing knowledge and awareness of invisible difficulties, access to vocational rehabilitation and employer and colleague support are addressed.

This chapter has discussed the four emergent themes in depth and highlighted the key findings. Chapter seven next presents a new return to paid work conceptual framework that I have developed directly from the findings. Conclusions and recommendations have been generated to inform future practice and are also presented in chapter seven.

Chapter 7 Conclusion

7.1 Introduction

Chapter two presented the background and context of the research and a critical baseline of existing literature and knowledge. By the conclusion of chapter two it was established that there was a need to know more about, and how to more effectively help individuals following a brain injury to return to paid work. Chapters three and four explained the research methodology and approach used to collect and analyse data from both injured individuals and employers with lived experience of this phenomenon. Chapter five presented the descriptive research findings, and established both barriers and success factors in relation to return to paid work from all of the participants' lived experiences. Chapter six discussed the four final themes that emerged. Following evaluation of the research findings, I have been able to develop a conceptual framework that will facilitate return to paid work rehabilitation of individuals following an acquired or traumatic brain injury. This chapter demonstrates new learning, a mastery of the existing knowledge and significant researcher reflection. It also presents an overall evaluation of the research findings whilst directly demonstrating achievement of the research aims and objectives.

This chapter brings my research to a conclusion. It starts with presentation of the theoretical underpinnings, the background, and the conceptual framework to facilitate return to paid work rehabilitation of individuals following a brain injury. The research conclusions and the seven conceptual framework elements are then presented. This is followed by reflections about brain injury and my research journey. Methodological limitations, generalizability, dissemination of my research findings and future research opportunities are then reviewed. The chapter concludes with recommendations being made, implications for future practice being presented and a final reflection.

7.1.1 The conceptual framework to facilitate return to paid work rehabilitation of individuals following acquired or traumatic brain injury

It has previously been acknowledged that paid work is valued in industrialised, Western societies, and that most adults expect to be in gainful employment most of their adult life (Winefield *et al.*, 2002). Work can be therapeutic, but the opportunity to work and the amount and quality of social connections surrounding it are important to our well-being (Waddell and Burton, 2006; Randall, 2015). I have developed the following conceptual framework from evaluation of the research findings and the theoretical underpinnings of the framework are next presented. They are followed by presentation of the background and need for the framework, and then the conceptual framework itself.

7.1.2 The theoretical underpinnings of the conceptual framework

This conceptual framework has been developed from, and is underpinned by several theories including occupation, grief and loss, self-identity and social inclusion (Yerxa *et al.,* 1989; Wilcock, 2007; Kubler-Ross and Kessler, 2005; Erikson, 1980; Belle-Isle and Benoit, 2014).

Occupational theory underlines the importance and need to acknowledge the occupational nature of individuals following a brain injury. This theory underpins the need to address resultant experiences of occupational disruption, dysfunction, imbalance, deprivation, alienation and injustice, and how they impact upon daily occupations, roles, relationships, capabilities and identity (Townsend and Wilcock, 2004; Munoz *et al.,* 2011; Dur *et al.,* 2015).

Kubler-Ross and Kessler's (2005) theory and stages of grief following loss directly link to the experiences of individuals following a brain injury. Kubler-Ross and Kessler (2005) acknowledge and recognise loss of occupations, roles, relationships, capabilities and pre injury identity following a brain injury and the need to adjust. In relation to self-identity, the work of Erikson (1980), Keilhofner (1992) and Kubler-Ross and Kessler (2005) all directly relate and overlap. Kubler-Ross and Kessler (2005) stress the importance of acknowledging and recognising the perceived loss of identity, Erikson (1980) highlights the need for a balance between an individual's sense of self over time and their fragmented sense of self, and Keilhofner (1992) underlines theoretical ideas about the self and how these can be applied to theories that address people's engagement in occupations.

Following a brain injury individuals struggle and need help to acknowledge, recognise and to adjust to their loss of occupations, roles, relationships and capabilities and to establish their new emerging identity, and this dynamic process is acutely experienced by them. Links exist between the underpinning theories in relation to the need for these individuals to feel valued and a sense of belonging, and the importance of promoting their social inclusion to improve their health, quality of life and sense of wellbeing (de Haan, 1998; Christiansen, 2000; Wilcock, 2007). Social inclusion and adjustment following a brain injury can be enabled by helping these individuals to experience meaningful occupational engagement, to feel valued, connected, to have a sense of belonging, through relationships, membership in social groups and by helping them to see how they can fit in.

My conceptual framework, whilst underpinned by established theories and principles, needs to be designed and actioned in practice to improve the return to paid work rehabilitation of brain injured individuals.

7.1.3 The background and need for the conceptual framework

The need for more research in the United Kingdom about factors impacting return to paid work following a brain injury has been highlighted, in addition to the need to better understand the lived experiences surrounding their return (Friedland and Potts, 2014). This is in keeping with poor international return to paid work rates and the need for further knowledge to address this (Walker *et al.,* 2006; Bjorkdahl, 2010). Literature suggests that factors such as cognitive difficulties, fatigue, low mood, reduced self-awareness, behavioural and psychiatric problems can impact return to paid work, but this literature in itself does not help to inform strategies, approaches or improvements for future practice (Radford *et al.,* 2013; Willmott *et al.,* 2014). These acknowledged factors, whilst informative, are not currently connected to any form of practical or vocational approach. In chapter six the established research participants' feelings of occupational alienation had arisen due to their difficulties returning to paid work, the absence of any guidelines, and because they had to find their own ways back to paid work. My conceptual framework is based on and developed from evidence of lived experience and directly addresses the issues experienced by the research participants to form the basis of a way of addressing and responding to their needs.

The conceptual framework is research and evidence based. It addresses areas of collective practice that appear to not be currently accessible, nor included in current vocational and return to paid work programmes or rehabilitation approaches. The framework will not only help develop occupational therapy vocational rehabilitation guidelines, but will also help therapists to integrate a research evidence based approach into their practice (Taylor, 2007; COT, 2009; 2013). Had this conceptual framework been available to the research participants, I believe that it would have increased their knowledge about their brain injuries, improved their experience and quality of recovery, and offered them a more effective opportunity to have returned to paid work.

Despite literature suggesting that vocational rehabilitation may increase return to work rates, little research has been carried out reviewing the specific contents of vocational rehabilitation and successful return to work outcomes (Tyerman, 2012; Phillips and Radford, 2014). In addition, less is known in relation to the most effective vocational rehabilitation approach; therefore it is no surprise that limited guidance currently exists. There is also little detail evident regarding how practically individuals following a brain

injury can more effectively return to work. Current practice varies from general work based skills training to more specialist approaches and lacks sufficient detail to replicate or has been implemented within a different culture (Holzberg, 2001; Fadyl and McPherson, 2009; van Velzen *et al.,* 2015).

It has been suggested that basic work skills training is less effective than supported employment, and this is augmented within the research findings and reinforced within the conceptual framework (Holzberg, 2001; Ross, 2007). Based on the evidence of need shown by the research participants, the conceptual framework places minimal focus on work skills or job retraining. Its core focus addresses individuals' occupational natures, drives and needs, support to help them deal with loss and grief, and facilitation of adjustment for both them and those involved following a brain injury. This would better facilitate a successful return to paid work.

My aim was also to develop a rehabilitation approach that would benefit not only individuals following a brain injury but also those directly involved. My intention was to develop a framework that would reflect the overall general description of the situated structure of the phenomenon. It was also seen essential that the framework and its content should be easy to follow and to understand, as well as easy to adopt, activate and incorporate into existing vocational rehabilitation approaches and workplace environments.

The conceptual framework is presented and illustrated within Figure 1, *7.1.3.1*. It is recommended as an approach for individuals following a brain injury, their families/carers, health and social care professionals, work colleagues and employers to use to facilitate and guide return to paid work. Illustration of the conceptual framework is followed with an explanation of the seven conceptual framework elements, and then presentation of the research reflections, recommendations and conclusions.

7.1.3.1 Figure 1: An illustration of the conceptual framework

The following conceptual framework and conclusions are original and have emerged directly from the research data. I hope that they will provide an innovative new way to help individuals, their employers, professionals and relevant others to plan and manage return to paid work following a brain injury.

The numbers one to seven within the framework illustration represent the seven elements contained within it, and are synchronised with the same numbers and explanatory text to follow within 7.2. In the illustration one asterisk (*) indicates that both of these elements need to be addressed at the same time, two asterisks (**) indicates that this element needs to start prior to return to paid work, and three asterisks (***) indicates that these elements may occur simultaneously or separately.

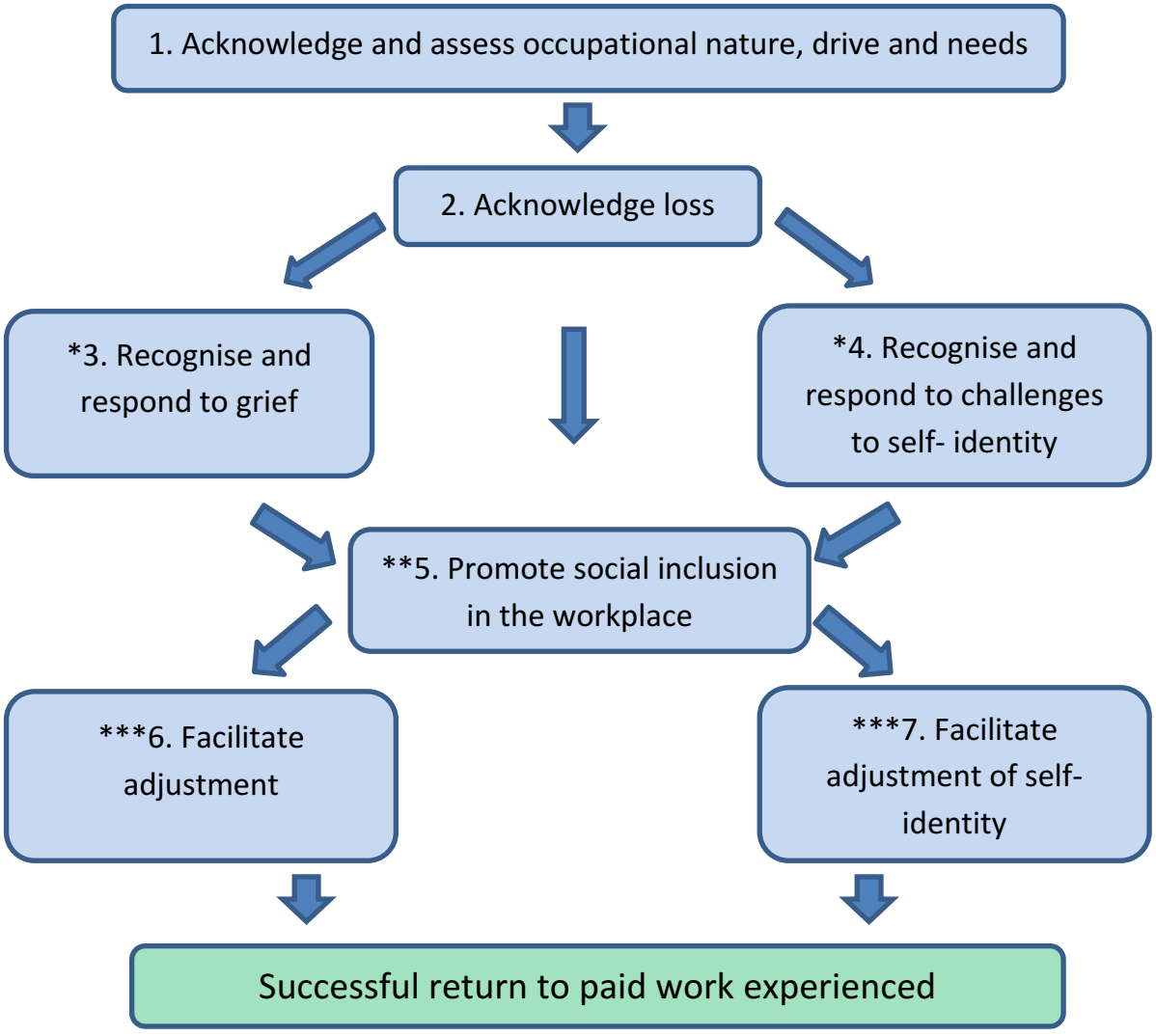


Figure 1: An illustration of the conceptual framework

7.2 The research conclusions and the seven conceptual framework elements

The numbers one to seven within the illustration of the conceptual framework previously presented in *7.1.3.1* are synchronised with the numbers and explanatory text that follows.

1. Acknowledge and assess occupational nature, drive and needs

Following a brain injury, individuals need to be occupationally engaged at an acute and early stage of their recovery, and to be doing occupations that they have some control over and that provide them with a sense of connectedness, purpose and meaning. It is essential for health and social care professionals involved to acknowledge and assess individuals' occupational nature, drive and needs and their drive to return to work to ensure that they do not return too quickly and before they are ready.

The meaningful occupation of work provides these individuals access to feelings of satisfaction, self-esteem and financial security, and can promote their recovery if their return to work is not too early. Work includes more than financial gain to them, and it is a way for them to get back to the person they were, that makes them feel valued, like they belong and enables them to once again contribute to society.

Occupational disruptions include resultant fatigue, poor memory and transport and benefit difficulties. Barriers such as fatigue, memory problems, driving restrictions and coming off of welfare benefits are currently poorly understood and require further research evidence to minimise occupational dysfunction. This understanding would allow these individuals to fulfil their pre injury values, roles, habits, occupations and their sense of self as far as possible.

Prior to return to work these individuals and their employers need to be provided with knowledge from health and social care professionals about resultant occupationally disruptive and dysfunctional barriers, and advice to help them to balance, restructure and to know how to reengage in productive occupations. Recognition of these individuals' occupational drivers, disruptive barriers and their need to balance, restructure and reengage in productive and healthy occupations is imperative for successful return to paid work to be achieved.

2. Acknowledge loss

Following a brain injury, loss is experienced in relation to pre injury roles, capabilities, occupations, relationships and individuals can experience threats to their self-identity. Most significant role loss(es) relate to worker and driver roles. These are often experienced at the same time as individuals are trying to maintain control despite experiencing threats to their self-identity and fears for their future. An increased awareness for everyone involved is needed of the impact of loss in relation to these roles. By those involved acknowledging loss(es) prior to return to paid work, planning can include and ensure that sufficient support is put in place to help individuals, their employers and colleagues to prepare to deal with loss and to facilitate a successful return.

***3. Recognise and respond to grief**

Grief is experienced when individuals following a brain injury start to acknowledge their loss(es), which may be prior to or on return to work. If they return to work too quickly and fail they may be in denial and still grieving.

All involved need to have an awareness of the five stages of grief: denial, anger, bargaining, depression and acceptance (Kubler-Ross and Kessler, 2005). These stages need to be recognised, and that an individual will grieve before returning, on, or after returning to work. If grief reactions such as ongoing denial, depression, anxiety, fatigue or grieving for a loss of their self are experienced, responses need to include health and social care professionals and employers slowing down the return to paid work plan. This is important as these grief reactions can be direct barriers to return to paid work.

*****Recognition and response(s) to grief should be considered and management strategies put in place prior to return to paid work and in collaboration with *recognition and response(s) to challenges to self-identity as * indicated within the conceptual framework illustration in *7.1.3.1.*

***4. Recognise and respond to challenges to self-identity**

Following a brain injury, individuals will experience threats, challenges to and/or a perceived loss of their pre injury self-identity, and are likely to be unaware that this is part of or as a consequence of their brain injury. They will experience a drive to return to their previous self and life at a time that they may also be grieving the loss of their pre injury

roles, capabilities, occupations and relationships. They may feel the need to fight for their identity to maintain their sense of self, and may use return to paid work to restore their sense of pre injury identity and to help them to form a new identity.

Prior to return to paid work planning, health and social care professionals and employers need to include time for individuals to grieve and receive support whilst they identify strategies to help them to re-develop their self-identity. Work may be used by them to maintain their sense of self and self-esteem. Support is required if anxiety and depression are experienced when individuals realise discrepancies between their pre and post injury identities. The use and acknowledgement of an identity anchor or transitional identity to facilitate recovery may be useful, and may help them to establish their new emerging identity (Chamberlain, 2005; Gendreau and de la Sablonniere, 2014). An increased awareness is needed by everyone involved that feelings of depression, grief, anxiety and reduced self-esteem may be experienced during the time needed for an individual to mourn their pre injury identity.

*****Recognition and response(s) to challenges to self-identity should be considered and management strategies put in place prior to returning to paid work and in collaboration with *recognition and response(s) to grief as * indicated within the conceptual framework illustration *in 7.1.3.1.*

****5. Promote social inclusion in the workplace**

The invisibility of ongoing difficulties such as fatigue, poor memory, concentration, reduced confidence, low mood and planning ability following a brain injury are a major factor impacting social inclusion on re-entering the workplace. These ongoing difficulties are invisible to colleagues to the extent that they may be doubted as genuine. Misconceptions occur due to the public misattributing the actions of people with brain injuries. This is specifically regarding the absence of visible markers of injury and comparisons being made between people with a brain injury and their peers, rather than comparisons being made with their pre and post injury abilities. These misconceptions in addition to the public's lack of knowledge of brain injury and the recovery process can lead to discrimination. It is unlawful to discriminate against disabled individuals, and if they are socially excluded this leads to them experiencing marginalisation and alienation (DDA, 1995). To minimise discrimination, misconceptions and to promote social inclusion

it is important, prior to return to work, for health and social care professionals to provide knowledge and understanding to the individual and the work force in relation to brain injury and return to paid work, and how to manage subsequent invisible difficulties.

Generalisation of the limited predictions available in relation to return to paid work success following a brain injury is difficult due to the differing methodologies and injury variables involved. More consistent predictions are where an injury is not too severe, an individual is self-aware, between the ages of 17–25 years of age, where substance abuse is not evident, when individuals are able to engage in activities demanding cognition and interpersonal skills and are working in a supportive work environment (Van der Horn *et al.*, 2013). It is therefore important for health and social care professionals to provide ongoing support.

Early access to vocational rehabilitation is recommended, but the best approach to vocational rehabilitation cannot be made, nor comparisons drawn across models due to methodological variation, so limited guidance exists regarding how to identify the best option (Phillips and Radford, 2014). Health and social care professionals need to provide early management strategies to deal with fatigue, driving ability and driving process awareness to promote success. Very gradual phased and supported return to paid work is essential for successful employment. The workplace culture needs to be supported by health and social care professionals to facilitate mutual respect, positive communication and civility.

Employers need to be provided with knowledge regarding ongoing brain injury difficulties and the recovery process in order to promote social inclusion in the workplace. Colleague support is also a requirement for successful return to paid work. Colleague initial reactions are often positive, but may change if they perceive that a job is not being done properly. The degree of colleague acknowledgement and acceptance of a brain injury impacts how inclusive they will be in the workplace. Workplace adjustment following a brain injury is harder where colleagues do not understand that ongoing, invisible difficulties are associated with a brain injury, therefore it is important for health and social care professionals to provide them with this knowledge and understanding.

Prior to return to paid work colleagues and employers need support from health and social care professionals to design management strategies for potential cognitive and/or

behavioural issues in the workplace, as well as planning to make the returning individual feel valued and that they will fulfil a meaningful role. Ongoing support is required for both the individual and work place colleagues in order to sustain return to work. There is also a need for health and social care professionals to provide training to support increasing injured individuals' insight, self-awareness, and to manage anxiety and mood difficulties especially related to adaptive work behaviour.

**** Promotion of social inclusion in the workplace should start prior to return to paid work and colleagues and employers informed about it in advance of the return as ** indicated within the conceptual framework illustration in *7.1.3.1*. This conceptual framework element should also co-ordinate with both of the final two elements (***facilitate adjustment and *** facilitate adjustment of self-identity).

*****6. Facilitate adjustment**

Individuals following a brain injury face injury related fatigue, cognitive problems, behavioural difficulties, environmental and relationship obstacles. Health and social care professionals need to provide further knowledge about their injury, and how it will potentially impact their life for them to be able to adjust. Specifically recognising grief, supporting recovery and helping injured individuals to avoid reliving grief all accelerate and promote their successful adjustment. Acceptance of changed abilities or disabilities begins when individuals start to do something about their difficulties. Adjustment follows acceptance of the consequences of a brain injury when individuals realise that they have changed and need to adjust.

Acceptance of a disability appears to positively affect an individual's ability to work, and not accepting a disability can be a barrier to successful return. Support and guidance from health and social care professionals is needed for employers and individuals following a brain injury to facilitate injured individuals' acceptance and adjustment prior to and during return to paid work. The invisibility of ongoing injuries is a major problem and professionals, employers and colleagues need to be better informed about injury invisibility to combat social stigma and to facilitate adjustment.

Injured individuals compare everything to their previous lifestyle. Rehabilitation needs to focus them and employers to embrace their new lifestyles, and not to return to previous

lifestyles. Rehabilitation needs to inform them and their employers about subsequent injuries, the consequences and impacts to potentially expect and the need to focus on adjusting. An individual's ability to understand is likely to influence their successful adjustment, and there needs to be awareness that continued and ongoing denial may be a barrier and can prevent recovery and may require more specialist support.

******* Facilitate adjustment and ******* facilitate adjustment of self-identity, as *** indicated within the conceptual framework illustration in *7.1.3.1,* may occur simultaneously or separately, but both need to take place to promote successful and sustained return to paid work.

*****7. Facilitate adjustment of self-identity**

It is crucial that individuals following a brain injury are allowed to mourn their lost self, to explore the distinctions between their pre and post injury selves, and to be able to reconstruct their self-identity. Health and social care professionals need to help them to change their previous views of themselves, and to embrace their new identity. Increasing self-awareness promotes changes to an individual's self-identity. It is necessary that all involved support their mourning of their lost self. To facilitate adjustment of self-identity they need to explore connections and distinctions between their pre and post injury selves and use these strategies to successfully facilitate the reconstruction of their new self-identity, especially their occupational identity. Support is required whilst individuals redefine their self-identity.

Professionals and employers need to enable a new status for injured individuals whilst making connections between their past and new statuses. Rehabilitation needs to inform individuals and employers about the need to focus on adjusting to be a new person, rather than the pre injury person. Being in a supportive environment, having the time, and feeling valued and acknowledged are factors that help individuals to make these adjustments.

The effect of a brain injury on occupational identity is not currently well understood. Successful return to paid work and restored occupational identity boosts the self-esteem of these individuals. Further research and a deeper understanding of occupational

identity following brain injury and competence could influence the success, process and timing of their occupational adaptation.

Adjustment of self-identity is a struggle, may take years and may never be achieved. Group membership and acknowledgement of others lends meaning to and strengthens individuals' sense of self. For reconstruction of self-identity to be satisfying following a brain injury the individual's refined self-identity needs to be valued by them and others. Health and social care professionals need to help them to appreciate how they can fit in and be treated like a person of worth.

******* Facilitate adjustment of self-identity and ******* facilitate adjustment, as *** indicated within the conceptual framework illustration in *7.1.3.1,* may occur simultaneously or separately, but both need to take place to promote successful and sustained return to paid work.

7.3 Reflections about brain injury and the research journey

Over the last 30 years, whilst working with individuals following a brain injury, it feels as if the general public's understanding has slightly improved in relation to the complexity and overwhelming impacts of a brain injury. I have always believed it crucial to learn from the lived experiences of service users, and on reflection, subjectively, return to paid work for these individuals appears marginally easier than it was 30 years ago, and that some progress may have been made.

Having now explored this phenomenon in depth however, it is a remarkable achievement that these individuals manage to return to paid work at all given the barriers that currently exist. Despite some areas of good practice, current policy and rehabilitation in England is not facilitating their successful return to paid work (DH, 2005; Black and Frost, 2011; DH, 2012; NICE, 2014). Rehabilitation services are either not available to these individuals or currently do not provide effective, sufficient rehabilitation or evidence based pathways to facilitate their successful return to paid work (COT, 2009; Tyerman, 2012). Policy, pathways and services need to be reviewed and improved to better target enabling these individuals to return to productive occupation and occupational roles. These appear essential to promote their future health and well-being and their ongoing ability to contribute to society (DWP, 2014b; Headway, 2014; Phillips and Radford, 2014). There is also a need for more longitudinal research studies as the recovery journey

following a brain injury seems to be much longer than the standard research periods within existing literature.

The philosophies of phenomenology and occupational therapy have complimented each other during my research journey. They have allowed me to bring together my professional identity, whilst researching within my life world, with the lived experiences of individuals following a brain injury and employers in their life worlds (Finlay, 2011). The use of a reflective diary and reflexive approach have been crucial to orientate and facilitate bracketing and reflexivity throughout, but most effective during descriptive data analysis (Finlay and Gough, 2003; Archer, 2010). My most important objective has consistently been to stay true to the descriptions of the research participants as so many misconceptions, assumptions and interpretations already exist around brain injury (McClure, 2011). Staying true to participant descriptions, although a priority, was challenging until I realised where I needed to sit on the descriptive interpretive continuum (Giorgi, 1997).

The Giorgi descriptive approach, whilst challenging to use and manage at times, in limiting itself to the data it provided, eventually provided strength and rigour. This enabled the true descriptive lived experience data to emerge, for me to have confidence in the findings and that they are true to the phenomenon (Giorgi, 2006). This methodological strength also promoted confidence that the final themes are grounded in the descriptive participant data. My development and experience using free imaginative variation, responsive-reflective writing and categorial intuition all helped to provide an understanding of the phenomenon as a whole, and have resulted in my confidence that the resultant conceptual framework, conclusions and recommendations have come directly from the participants' lived experiences (Van Manen, 1990; Husserl, 2001; Giorgi, 2006).

It can be argued that all research contributions to an under researched area may be valuable, however it is still important to consider the research methodological limitations, generalizability, dissemination and future research opportunities before considering application. These are individually considered in 7.4.

7.4 Methodological limitations, generalizability, dissemination and future research

There is no doubt that my findings have established key issues in relation to the return to paid work following a brain injury phenomenon. As in all phenomenological research however, despite my research pointing to aspects of the experience, it must at the same time be acknowledged that understanding may not be complete as findings can vary dependent on participant diversity, culture, level of awareness, emotional and cognitive abilities, reliance on self-report and brain injury severity (Giorgi, 2000a). It is therefore important to explore factors that could limit and influence the interpretation of my findings. The research limitations, generalizability, dissemination and future opportunities are next reviewed.

7.4.1 Limitations

I collected rich descriptive phenomenological data; however this has to be considered a potential limitation. My research was limited to and included only data from a small group of 16 brain injured participants and 11 employers, so my findings are not representative of an entire population, nor do they represent the views of others involved. In addition, the employer data took a year to collect due to challenging recruitment and may be limited. It has to be acknowledged that the employer data may have included mostly motivated employers and not be representative of all employer experiences.

The use of interviews also relied on participants recall from several years before and such a retrospective view may have limited the range and depth of participant descriptions (Van Manen, 1990). Reliance on the on self-report of injured individuals may have been limited by their injury severity, impact of cognitive impairment, self-awareness, and by the fact that it could not be independently verified. Interview data collected needed to take participants at face value and may have contained bias such as exaggeration.

Despite adherence to the rule of epoche and my use of bracketing of prior knowledge, it has to be questioned that beyond reasonable doubt I was able to suspend all prior knowledge of brain injury, and that my theoretical biases did not inadvertently influence some decisions and unknowingly influence the research (Giorgi, 2000b).

Being a sole researcher may also have limited the credibility of my findings, my presence during data collection may have inadvertently affected participant responses, as well as me being an informed interviewer and experiencing any unconscious bias that may have influenced data collection or analysis. The findings may also be limited due to this being the first time I had used this research design and methodology, and my adherence and bias towards Giorgi's phenomenological approach may have impacted my interpretation of the findings. Despite the descriptive phenomenological analysis used being strong and robust, it does not represent views outside of descriptive phenomenology.

7.4.2 Generalizability

Generalizability describes the extent to which research findings can be applied to settings other than that in which they were originally researched (Myers, 2000). Generalizability is acknowledged as a quality standard in quantitative research, but is more controversial in qualitative research, and qualitative research can be criticised for its lack of generalizability, for example from a group of specific participants to the entire population generalizability of qualitative research findings are not usually expected (Myers, 2000).

Although my findings clearly describe current return to paid work experiences following a brain injury phenomenon, they may have limited generalizability due to being only the experiences of 27 participants within and across central and southern England. My findings are from a relatively small sample, so cannot be generalised to the entire population. The generalizability of my phenomenological findings is limited to the experiences of my participants, and data may have differed if collected from a different geographical area, socially diverse group, and included different injury related variables. In addition, the majority of the participants following their brain injuries had not accessed vocational rehabilitation and had varying return to paid work timescales. My findings may therefore have limited transferability.

Conceptual and theoretical generalizability relate to the extent to which my research conceptual and theoretical findings can be applied to other settings. My research has established key findings that could be recognised by others and built upon in order to challenge future practice. With the aggregation of my findings to other similar findings, this could allow theory to be built and the generalizations produced would be no less legitimate than one individual finding.

A particular context can also limit transferability, and therefore my findings may be less generalizable in different contexts. For example, individuals can be significantly influenced by different settings and contextual variables such as physical space, roles, and values (Delmar, 2010). For example, my use of snowball sampling, although helpful to recruit appropriate participants, may have made it difficult to generalize to broader contexts. In relation to context generalizability however, I have made my research context clear and other researchers will be able to assess the doubleness of the situation as described by Delmar (2010) as being both typical and unique. The transfer of my findings therefore could be generalizable to similar and recognisable contexts and settings.

My findings cannot be generalised to the entire population. Aggregation of my findings with other similar findings would allow conceptual and theoretical generalizability. By being clear about my research context, transferability and contextual generalizability of my findings could be possible to similar contexts. In order to triangulate my findings however, there is a need for further research within, and also beyond the UK, and to also look at the phenomenon under different contexts to find similarities that could have wider generalizability.

7.4.3 Dissemination

A dissemination plan of my PhD findings that reports both my dissemination activity and achievements from 2010 to date can be found in Appendix 22. This plan includes academic, non-academic and future dissemination strategies. The non-academic dissemination strategies have been bolded to highlight them within the Appendix.

7.4.4 Future research opportunities

Further research is needed to extend my findings, in addition to me establishing post-doctoral funding to pilot and measure the effectiveness of the conceptual framework that I have developed.

7.5 Recommendations and implications for future practice

The following recommendations identify new issues and aim to provide a more effective and improved approach to return to paid work following a brain injury. Both the

recommendations and implications for future practice are presented in relation to and using the four themes that emerged from my research: occupational needs; loss, grief and adjustment; self-identity; and social inclusion and return to the workplace. I address each individual theme by firstly making recommendations and secondly with the relevant implications.

7.5.1 Recommendations in relation to occupational needs

There are six overall recommendations in relation to occupational needs. Four of the six are key recommendations that can be directly impacted by my research, and the remaining two are worth bringing to the attention of Central Government.

Department of Health, Department of Work and Pensions, Social and Council Services staff need to be informed, and to make individuals following a brain injury and their employers aware of the relationship and timing of an early decision to return to paid work. They specifically need to inform them about the impact on the health of these individuals and their likely return to paid work success. This increased awareness could make their return to paid work more effective, satisfying and successful, and reduce the likelihood of failure and the loss of pre injury employment.

All personnel involved (from acute to long term follow up), employers, relevant others and individuals following a brain injury need to be trained to have a better understanding of occupational disruptive barriers such as fatigue, memory problems, driving restrictions and driving ability. This training should be provided by relevant Allied Health Professionals involved as early as possible and include how to manage ongoing fatigue, a poor memory, to use transport and return to driving processes. This would help fulfil pre injury values, roles, habits, occupations and individuals' sense of self, as well as promote occupational justice and social inclusion.

Return to paid work occupational assessment and outcome measures need to be redesigned by occupational therapists to include assessment and outcome of individuals valued occupations, roles, relationships and identity needs as well as capacity needs. These redesigned measures would demonstrate effectiveness of occupation-focused interventions, and provide evidence of the value of occupational therapy to return to paid work vocational rehabilitation.

Following publication of my conceptual framework and findings, these can be disseminated, used and built upon. My findings could be included in both the College of Occupational Therapists guide to occupational therapy vocational rehabilitation practice (2009) and the Acquired Brain Injury Guide for occupational therapists (2013) when they are next updated. In addition, Health and Social Care professionals can contribute to and use my findings to disseminate, establish and provide return to paid work evidence based guidelines in England. These guidelines could be used by personnel involved, employers, relevant others and individuals following a brain injury to better inform them about resultant occupational barriers and enable more successful return to and reengagement in paid work.

The remaining two recommendations are worth making to Central Government. Firstly that the current benefits system relevant to brain injured individuals needs revising and secondly that current overall brain injury spending in England requires review. The benefits system needs to be more accessible and supportive of return to paid work and easier for employers, injured and the public to understand. Currently the Departments of Health and Work and Pensions, Social and Council Services and the Inland Revenue all work in isolation, both practically and financially, making it easy for injured individuals to fall between services. Current departments could be redesigned to develop one central funded, integrated and collaborative brain injury rehabilitation pathway that could facilitate more collaborative working, effective return to paid work for these individuals and invest in future income contribution. This would promote occupational justice.

7.5.2 Implications in relation to occupational needs

Implications for practice include contributing to the development needs of future occupational therapy vocational rehabilitation. In addition, more directed and effective occupational engagement of these individuals to promote their future health, as well as minimising discrimination and fostering their recovery in the workplace with the provision of return to paid work guidelines.

An occupational shift in the way assessment and outcome is currently measured would collect occupational outcome data that will generate evidence for future occupational effectiveness. Redesigned occupational needs assessments would no longer only focus on improving capacity issues such as fatigue, memory and concentration, but also focus on

promoting occupational balance, minimising occupational dysfunction, deprivation and alienation.

Implications of the two recommendations to Central Government regarding changes to current services would prevent these injured individuals from missing essential information and rehabilitation. A redesigned brain injury rehabilitation pathway would integrate all departments, and provide a collaborative service to begin following a brain injury through to an individual's work or occupational destination.

7.5.3 Recommendations in relation to loss, grief and adjustment

There are four key recommendations in relation to loss, grief and adjustment.

Health and social care professionals need to design and provide information to increase individuals understanding of loss as a consequence following their brain injury and include the stages of grieving. This will increase their self-awareness of grief reactions such as denial, depression, anxiety and fatigue and provide them with strategies and support.

Health and social care professionals also need to improve assessment of perceived loss and its impact on individuals following a brain injury in relation to their roles, especially worker and driver, their capabilities, occupations, and relationships. The impacts of loss can then be acknowledged and responded to in order to facilitate adjustment post injury.

The five stages of grief need to be assessed and managed by all professional staff involved, especially for those returning to paid work quickly. Grief can then be managed transparently to facilitate adjustment.

Training needs to be prioritised and provided by the Departments of Health and Work and Pensions to inform health and social care professionals, employers and individuals following a brain injury about the invisibility of ongoing difficulties and their potential impact. This would combat social stigma in the workplace.

7.5.4 Implications in relation to loss, grief and adjustment

Implications include this training being provided to medical and undergraduate and post graduate health and social care professionals, Department for Work and Pensions staff and individuals following a brain injury about brain injury loss, grief and how to facilitate adjustment. Vocational rehabilitation should include assessment of loss, grief counselling

and coping strategies to inform employers and individuals following a brain injury how to manage loss and adjustment in the workplace.

7.5.5 Recommendations in relation to self-identity

There are three key recommendations in relation to self-identity.

Health and social care professionals need to encourage individuals following a brain injury to use an identity anchor or a transitional identity to help them recognise, respond to and embrace their new identity, and to try not to return to their previous identity. This would enable them to make connections between their past and new statuses to facilitate recovery and adjustment of their new emerging self-identity and continuity in their sense of self.

Further research is recommended to increase understanding of occupational identity and how this could be used to help these individuals to adjust to their new self-identity.

Health and social care professionals need to be trained and to address challenges to an individual's self-identity following a brain injury in return to paid work programmes and vocational rehabilitation. This needs to include time and support for individuals following a brain injury to mourn their previous identity and to help them to understand and come to terms with their changing identity.

7.5.6 Implications in relation to self-identity

Implications for practice include recognition of the impact of self-identity changes following a brain injury and the provision of necessary training about self-awareness, loss of self and self-identity issues for all professional staff involved. Vocational rehabilitation needs to address and include self-identity changes, assessment and provide recovery strategies to help individuals come to terms with their changing identity.

7.5.7 Recommendations in relation to social inclusion and return to the workplace

There are three recommendations in relation to social inclusion and return to the workplace. Two key recommendations can be directly impacted by my research and one recommends further development of Government legislation.

Health and social care professionals need to ensure that existing vocational rehabilitation includes early fatigue and driving awareness and management strategies, self-awareness training, and addresses mood difficulties. Vocational rehabilitation also needs to involve,

include and inform employers and colleagues about brain injury. Specifically about the invisible ongoing difficulties as early as possible and before return to work takes place. This would manage expectations, tackle potential discrimination and foster social inclusion.

The effectiveness of current vocational rehabilitation needs further research so that future vocational rehabilitation development is based on research evidence and is cost effective. Future return to paid work research needs to include more longitudinal studies of longer than one year duration as the brain injury recovery journey appears much longer than existing standard research periods. In addition, more research is needed about the ability to sustain work.

Government legislation, whilst attempting to help, needs to be further developed (DDA, 1995; DH, 1999; 2005; 2012; NICE, 2014). Further Government legislation needs to guarantee the provision of effective vocational rehabilitation to all individuals following a brain injury, and the delivery of public education to tackle discrimination and social exclusion in the workplace.

7.5.8 Implications in relation to social inclusion and return to the workplace

Implications for practice would include provision of vocational rehabilitation that is responsive to user needs, more effective and evidence based, and a cultural shift taking place in public, employer and colleague awareness about brain injury and their perceptions of it. This would promote social inclusion.

7.6 Final reflection

My research findings and new contribution fill a gap in the current research literature and describe, for the first time, the return to paid work lived experiences of both individuals following a brain injury and employers of individuals following a brain injury in England.

My findings will move the literature on and add understanding as they have identified current barriers and success factors that impact the return to paid work of these individuals in England. My findings have also resulted in the development of a conceptual framework that can be used to facilitate future return to paid work following a brain injury, addressing key issues that I have established including occupational drive, loss, self-identity and social inclusion. Further strengths of my work include confirming that most return to paid work services in England currently do not appear to be evidence

based, are not available to everyone following a brain injury, and were ineffective for the research participants.

Key conclusions and further new knowledge to emerge from my research identified that due to the drive and occupational need to return to work of these individuals, currently they are at risk of returning to paid work too quickly to achieve successful outcome. Return to paid work is being used by them to find the person they were pre injury, to be where they felt like they belonged, were valued and were able to contribute to society. Their occupational needs strongly influenced my findings and echo Wilcock's (2007) belief that doing, being, becoming and belonging appear essential to health.

Two studies of the five established from the United Kingdom previously identified fatigue as an issue up to five years following a traumatic brain injury (McCrimmon and Oddy, 2006; Hooson *et al.*, 2013). My findings however established fatigue as not only the most common ongoing occupational disruption experienced by the research participants, but that it continued to be an impacting factor on average up to 12 years post injury. A further study from the United Kingdom looked at sustaining work following an acquired brain injury, and referred to the ability to travel to and from work as an issue (Macaden *et al.,* 2010). My findings confirmed that not only is transport and driving a barrier, but that it was the third most important disrupting factor described by the research participants. I have therefore confirmed and recommended that a much better understanding of post injury management of fatigue, memory problems, transport and driving restrictions and coming off welfare benefits is needed to effectively enable individuals following a brain injury to fulfil their pre injury values, roles, habits, occupations and sense of self.

Both the new knowledge generated from my research and the conceptual framework I have developed have the potential to have positive implications and impacts on practice for individuals following a brain injury, their families and carers, rehabilitation services, employers and colleagues. The conceptual framework provides a new and a very different approach to current vocational rehabilitation. In my researched opinion this will better prepare both individuals following a brain injury, employers and colleagues prior to return to paid work taking place. I anticipate that my conceptual framework will also extend the forefront of vocational rehabilitation for these individuals, and that it will be adopted to provide an updated common language, approach and a refreshed reference for redefining

intervention priorities and boundaries. A re-emergence of Romanticism, as described by Hocking (2008c), appears necessary for us to help these individuals to deal with softer issues such as finding themselves as this is much more difficult to work on in a medical, Rationale context.

From the accumulated new knowledge of my research and conceptual framework it is clear that following a brain injury individuals need to be better prepared before returning to paid work. Despite legislation, social exclusion is a reality that needs to be tackled to truly impact the future return to paid work success for individuals following a brain injury. A lack of knowledge appears to be driving discriminatory and exclusion tendencies. Gilworth *et al.* (2008) previously reported invisibility of difficulties as an issue in the north of England for 33 people following mild to moderate brain injuries six months post injury, however my findings identified invisibility as a key issue on average up to 12 years post injury. Injured individuals, their families and carers, health and social care professionals, employers and colleagues therefore all need to be better informed about the invisibility of difficulties to combat social stigma, misconceptions and social exclusion.

The main achievement of my research is that my new, unique and research based conceptual framework provides new meaning to the way future intervention strategies can be provided, further researched and developed to benefit individuals following a brain injury.

Appendix 1 Keywords and thesaurus terms used for the literature search

Keywords

- Return to paid work
- Brain injury

Thesaurus terms used

Return to paid work	Brain injury (including mild, moderate, severe)
Return to paid work	Brain injury
Return to paid employment	Acquired brain injury/ ABI
Return to paid occupation	Traumatic brain injury/ TBI
Return to work	Head injury/ies
RTW	Head trauma
Vocational	Intra cranial haemorrhage
Employment	Brain haemorrhage
Wage	Brain damage/trauma
Employment status	
Stability of employment	
Vocational rehabilitation outcome	
Occupation	
Re-employment	
Work re-entry	
Job re-entry	
Work experiences	
Self-employment	

Appendix 2 The literature review inclusion, exclusion and search strategy criteria

Inclusion

- Primary research
- English language
- Peer reviewed
- Published in the last 10 years (from 2003 to January 2014)
- Only to include later, additional data from Zetoc alerts which include the core research variables after January 2014
- Only to include cerebrovascular accident/stroke as part of an ABI publication and only where there is minimal cerebrovascular accident/stroke data i.e. more than half the sample group need to be non- cerebrovascular accident/stroke ABI

Exclusion

- Systematic or literature reviews
- Qualitative syntheses
- Posters
- Brain injury reports or guidelines
- Research that is solely about cerebrovascular accident/stroke, insurance, compensation, vocational rehabilitation, rehabilitation effectiveness, congenital injury/ies, or if related solely to brain injury symptoms (memory, attention, spasticity), general rehabilitation, post-traumatic stress, supportive employment schemes, vocational model evaluation, vocational service descriptions, army services

Search strategy

Boolean operators and truncation

Command	Purpose
AND	Look for articles that include all the identified keywords
OR	Look for articles that include any of the identified keywords
NOT	Exclude articles that contain this specific keyword

Appendix 3 The University of Northampton databases searched

The following databases were individually searched using the Northampton Electronic Library Search Online (NELSON) between 21/1/14 and 3/2/14.

- AMED
- ASSIA, ABI
- British Medical Journal
- CINAHL
- Cochrane Library and Database of Systematic Reviews
- Ingenta Connect
- Internurse
- Medline
- PubMed Central
- PsycNet
- Science Direct
- SAGE Journals Online
- Swetswise
- Taylor and Francis
- Trip Database Plus
- Web of Knowledge
- Wiley Online Library
- Zetoc

Appendix 4 Literature yield summary from each database

Database	Core literature
1. CINAHL	**Paid work:** • Ownsworth *et al.* (2006) • Tsaousides *et al.* (2009) • Soeker (2011) • Dawson *et al.* (2007) • Lundqvist and Samuelsson (2012) • Soeker *et al.* (2012a) • Van Velzen *et al.* (2011) • Fraser *et al.* (2006) • Gilworth *et al.* (2008) • Holtslag *et al.* (2007) • Parks *et al.* (2010) • Rubenson *et al.* (2007) • Levack *et al.* (2004) • Macaden *et al.* (2010) • Shigaki *et al.* (2009) • Hanlon *et al.* (2005) • Corrigan *et al.* (2007) • Fort *et al.* (2011) • Walker *et al.* (2006) • Björkdahl (2010) • Artman and McMahon (2013) • Power and Hershenson(2003) • Johansson and Bernspang (2003) • Kreutzer *et al.* (2003) • Soeker *et al.* (2012b) • Hooson *et al.* (2013) • McCrimmon and Oddy (2006) • Nimgade and Costello (2003) 28
2. AMED	• Ownsworth (2010) 1
3. ASSIA	0
4. BMJ	• Schönberger *et al.* (2011) 1
5. Ingenta Connect	0
6. Internurse	0
7. Medline	• Doctor *et al.* (2005) • Oppermann (2004) 2
8. PubMed	0
9. PsycNet	0
10. Science Direct	• Bonneterre *et al.* (2013) 1

11. SAGE Journals Online	0
12. Swetswise	0
13. Taylor and Francis	0
14. Trip Database Plus	• Grauwmeijer *et al.* (2012) 1
15. Web of Knowledge	• Franulic *et al.* (2004) • Machamer *et al.* (2005) 2
16. Wiley Interscience	0
17. Zetoc	• Forslund *et al.* (2013) • Rietdijk *et al.* (2013) • Benedictus *et al.* (2010) • van der Horn *et al.* (2013) 4
18. Zetoc alerts post initial search	• Friedland and Potts (2014) • Waljas *et al.* (2014) 2
19. Cochrane Database of SRs	0
20. Systematic reviews, syntheses, reports and posters	CINAHL • Saltychev *et al.* (2013)-systematic review • Van Velzen *et al.* (2009)-systematic review • Van Velzen *et al.* (2009)-systematic review • Stergiou-Kita *et al.* (2012)-qualitative synthesis • Kendall *et al.* (2006)-qualitative synthesis • Shames *et al.* (2007)-systematic review SAGE Journals Online • Athanasou (2003)-study review Web of Knowledge • McNamee *et al.* (2009)-evaluation of text • van Velzen *et al.* (2012)-poster Zetoc • Nightingale *et al.* (2007)-systematic review Hand search • Wehman *et al.* (2005) 11
Hand searched articles added	• Boake *et al.* (2005) • Petrella *et al.* (2005) 2
Overall yield included in background literature review	55 sourced in total less 11 reviews =44 total for literature review

Appendix 5 Summary of the 44 data yield and theme emergence

Author & publication date	Country	Aim	Study design	Data collection	Participants	Key findings	Strengths	Weaknesses or limitations	Theme emergence following coding and comparative analysis
CINAHL									
Ownsworth *et al.* (2006)	Australia	Investigated self-awareness and emotional wellbeing according to change in employment outcome with ABI (acquired brain injury)	12 month longitudinal study	Outcome measures: self-awareness of deficits interview, self-regulation skills, hospital anxiety depression scale, employment outcome	50 adults with ABI	Employment outcome not significantly associated with changes in self-monitoring or emotional wellbeing. Findings support that an increase in self-awareness is associated with improved employment status, although this relation is unclear and low levels of self-awareness may not preclude from functional gains Rehab needs focus on improving self-awareness	Significant difference found between employment groups and age, tendency for the improved employment group to be younger	Non parametric statistical methods used for all analyses Individuals in the stable employment group were significantly older than the improved employment group, suggests that older individuals (40 or older) less likely to return to work	Self-awareness and adaptation
Tsaousides *et al.* (2009)	USA	Examined employment related and general self-efficacy to perceptions of quality of life	Correlational	Outcome measure: employment related self-efficacy, general self-efficacy, perceived quality of life, unmet important needs	427 under 65 years with TBI (traumatic brain injury)	Significant correlations between income, injury severity, age at injury, and employment and quality of life. Return to work facilitated by increasing confidence in work related abilities and enhancing self-efficacy and will impact perceptions of well being	Perceptions of employability related strongly to quality of life and having increased confidence related to a sense of need attainment	No objective criterion to measure self-efficacy against	The meaning of work, quality and life satisfaction
Soeker (2011)	South Africa	Described perceptions and experiences regarding adapting to worker roles	Qualitative	Semi structured interviews	9 men and 1 woman with mild to moderate brain injury secondary to trauma	Provide insight into process of occupational adaptation and its link to individual's sense of competency and identity. Stigma caused loss of jobs and negatively affected obtaining new job. Tried to rebuild selves by finding contentment with their condition and rebuilding their self-concept and self-esteem	All reported low self-confidence. Family excluded as result of physical limitations. Feared unemployment post injury. Felt isolated. Reflection involved the mental separation from their previous life in an attempt to continue with life	Small study and in South Africa	Factors relevant to sustaining work and Self-awareness and adaptation
Dawson *et al.* (2007)	Canada	Investigated return to productivity 4 years post TBI	Prospective , cohort study	Demographic, injury severity, time to recover free recall, neuropsychological, physical, spiritual, environmental data	46 TBI and 14 friend/family member controls	Injury severity (time to free recall), physical status (pain) and psychological status (depression) important to understanding differences in productivity outcomes. Addressing pain, depression and coping in rehabilitation may have positive impacts	Scores for TBI significantly different than control for depression. Those not back at work significantly older	Sample size. No uniformity in how productivity measured	Factors impacting and predicting return to work
Lundqvist and Samuelsson (2012)	Sweden	Study significant factors supporting vocational rehabilitation after ABI	Qualitative	2 focus groups	1 group of 14 (8 men and 6 women) ABI and 2nd of professionals	Important to have a fighting spirit, positive attitude, a capability to change, to take control of own life, to learn to cope with symptoms. More important to have a job when have a disability as is a way to come back, feel belong and can contribute to society	Needed time to recover	Included 6 CVA/stroke participants. Small sample	Self-awareness and adaptation
Soeker *et al.* (2012a)	South Africa	Explored barriers and facilitators regarding return to work and lived experiences	Qualitative-phenomenology	In depth interviews	10 mild to moderate TBI	Barriers-2 themes; a sense of loss of former self and uncertainty about the future. Facilitators-1: participation in occupation enables recovery. Participants viewed the absence of a facilitator to be a barrier and inversely the absence of a barrier was viewed to be a facilitator	Participants; reduced concentration, memory, reduced insight, loss of self-confidence, underestimated by society, fear of unemployment, stigma related to BI, participation in occupation enabled growth and recovery	Small study and in South Africa. Only one female included	Factors relevant to sustaining work and Self-awareness and adaptation

Van Velzen *et al.* (2011)	Netherlands	Described limiting and facilitating factors re return to work	Qualitative content analysis	Semi structured interviews	12 Moderate-severe ABI (9 men and 3 women)	Most common facilitating factors: tiredness, the will to return to work, ongoing recovery, knowledge and support of employer, colleagues, occupational physician	Inform employers, colleagues, occupation physicians. Tiredness-unable to anything other than work needed longer time to recover. Perhaps ABI need longer time to return to work, reconsider sick pay criteria.		Factors impacting and predicting return to work
Fraser *et al.* (2006)	USA	Examined return to work and understanding the role of job complexity following TBI at 3-5 years post injury	Mixed methods	Structured interview, demographic info,	140 TBI workers, mild to severe, sample predominately male, mid 30s average, and high school education at time of injury	Participants most likely to maintain complex work were females, fewer alcohol problems, less severely injured, showed significant better neuropsychological functioning. Group never able to work more severely injured	Indicates job complexity needs more research	Only examined at one point in time	Factors relevant to sustaining work
Gilworth *et al.* (2008)	United Kingdom	Explored work related expectations and experiences of workers who had sustained mild to moderate brain injury	Qualitative-thematic analysis	Semi structured in depth interviews 4-6 months post injury	33 (11 females and 22 males), mean age 37, mild or moderate injury	Key themes; invisibility of their disability, continuing symptoms affecting their ability to do job, lack of advice. Return to work support systems were poorly coordinated and managed	Had returned to work too soon, lack of support in workplace, lack of info re brain injury	Sample from one single hospital in the north of England therefore not totally generalizable	Factors relevant to sustaining work
Holtslag *et al.* (2007)	Netherlands	Quantified the prevalence of return to work after major trauma and the determinants of post injury work status	Demographi c data	Multivariate logistic regression analyses	214 adults (age 16+) admitted from Jan 99-December 2000, who were full time employed at injury. 184 men and 30 women.	Following injury 58.4% (n=125) were able to return to work full time, 21.5% had a part time job and 20.1% did not return to work. Around 60% of patients returned to their pre-injury work status after major trauma		Large unselected group of consecutive severely injured patients included. Some participants had spinal cord injury, not generalizable	Global return to work rates
Parks *et al.* (2010)	USA	Hypothesised that employment rates amongst TBI survivors decrease following injury and remain depressed for an extended time	Mixed	State-wide surveillance system, telephone interviews	3522 TBI, (15 +) discharged alive from acute care hospitals	The pre injury employment rate was 67% which declined to 52% in the first year and slowly rose in subsequent years. Increasing severity of traumatic brain injury was associated with lower employment rate. Women who were employed full time before TBI were more likely to work part time after than men	Older aged likely to lose employment	Only 51% of sample was employed full time before injury	Factors impacting and predicting return to work
Rubenson *et al.* (2007)	Sweden	Explored experiences of return to work after rehabilitation, from the viewpoint of ABI	Qualitative content analyses	Open question interviews	8 ABI	Requires motivated ABI, flexible work, accommodating labour management, and prolonged environmental support. Participants; not received correct advice, great loss, fatigue which was accentuated by strong sounds, messy environments and stress. Risk of return to work too quickly because of finance pressure, manager and colleague support a prerequisite. Most needed to reduce working hours	Need support for a long period of time to reach balance and to obtain a functional working role	Small sample	Factors impacting and predicting return to work

Levack *et al.* (2004	New Zealand	Explored experiences of individuals who attempted returning to work following TBI, with emphasis on factors that related to perceptions of success and failure	phenomenology	interviews	7 moderate-severe TBI (4 men and 3 women)	Support the assumption that paid employment is indicative of success following TBI. Equally this was challenged where return to work contributed to catastrophic events, success was felt even though paid work was not, success in the workplace associated with factors other than hours worked or pay earned. Feelings of productivity frequently identified as success, sense of having done something worthwhile	Return to work a subjective experience. Negative experiences ranged from clinical depression to facing disciplinary action in workplace, to failing to adapt to restructured work or being fired. Poor management of fatigue, behaviour and hypersensitivity to background noise. Work needs to contribute to feelings of meaningful productivity, needs to be stimulating, creating positive sense of identity and self-worth without compromising success in non-work life		Factors relevant to sustaining work and The meaning of work, quality and life satisfaction
Macaden *et al.* (2010)	United Kingdom	Explored factors affecting sustaining ABI employment	Multiple case study	Semi structured interviews	8 cases (29 participants)-included ABI, family member, job coach, co-worker. ABI-4 single men in 20s, 3 divorced men in 40s and 1 married woman in 40s	Unconditional motivation, insight and ability to cope with cognitive and behavioural sequelae were beneficial to sustain work	Employers with personal experience of disability helped acquired brain injured	Had all completed vocational rehabilitation, 5 had severe TBI and 2 strokes and 1 subarachnoid haemorrhage. Drawback of qualitative studies is generalisability	Factors relevant to sustaining work
Shigaki *et al.* (2009)	USA	Determined outcomes for TBI in terms of employment status, income and public assistance received 2 years post	Non experimental longitudinal survey	Employment status, monthly income earned, public income at baseline and post 2 years from database	49 with TBI	TBI higher levels of employment and earned income than previously reported for 1 year post but continued to have declines	Costs of brain injury remain high for individuals, families and society as they move into more chronic stage of recovery	Results based on self-report of 49 TBI from restricted USA geographical location	Global return to work rates
Hanlon *et al.* (2005)	USA	Compared neuropsychological impairment and vocational outcome at 1 year in patients with traumatic subarachnoid haemorrhage (tSAH) and those without	quantitative	Data re neuro, neuropsych and vocational	100 moderate and severe TBI	Those with tSAH had significantly worse vocational outcome than those without	Depression likely to be a key factor	Self-reported mood on non tSAH significantly better	Factors impacting and predicting return to work
Corrigan et al. (2007)	USA	Determined if sex differences in employment 1 year post TBI	quantitative	Dataset re change in employment at 1 year post	3444 adults (2487 men and 957 women with TBI, aged 18-64 inclusive	Women more likely to decrease hours or stop working, except in oldest group (55-64yrs) in which men more likely to stop. Women showed a better pattern for employment outcomes as age increased. Decreased employment for women was more evident for those married, who were more likely to reduce hours or stop working	Need to consider occupations, if primary age earner, if children present, if partner violence cause of injury, if PTSD or depression	Significantly less women affected results	Factors impacting and predicting return to work

Fort *et al.* (2011)	France	Analysed factors associated with late return to work in road accident victims	quantitative	Questionnaires at 6 months and 1 year	608 cohort subjects	179 late to return to work	Type of journey, injury severity and intention to press charges factors predictive of late return to work. A low educational level associated with difficulty return to work for medullary (n=17) or cerebral lesions (n=18)	Injuries included head, face, neck, thorax, abdomen, spine, lower limb. 184 subjects lost to follow up	Factors impacting and predicting return to work
Walker *et al.* (2006)	USA	Evaluated return to work after TBI with focus on pre injury occupational category and return to work outcome	Prospective collaborative cohort study	In patient interdisciplinary rehabilitation programme and competitive employment at 1 year post	1341 moderate-severe TBI, aged 18-62. 77% male and predominately white (69%), with 22& African-American, 6% Hispanic and 3% other	Rate of successful return to work greatest for professional/managerial (56%), lower for skilled (40%) and lowest for manual labour (32%). Pre injury occupation, educational level, discharge FIM score, age, sex, marital status and hospital LOS each influence return to work. At 1 year post injury 39% were in either full or part time competitive employment	Type of occupation influences return to work and best amongst professional/managerial groups	Only at 1 year post and all had rehabilitation. Cognitive impairment measures not included. Geographically and socially diverse data	Global return to work rates
Bjorkdahl (2010)	Sweden	Followed up return to work after vocational neuropsychological programme to explore predicting return to work. Hypothesised that self-awareness would impact return to work	Quant and qualitative	Neuro psych, AMPS, Interviews about occupation at 1,2,3 and 5 years after programme	65, TBI median age 27, 39 men & 26 women, time since injury 6 months-27 years. 44.6% had TBI; the rest had sub arachnoid haemorrhage, encephalitis, anoxia, and consequences of treatment or resection of brain tumour	Before injury 77% were employed or studied and after injury 80% had no occupation. After 5 years 40% had return to work. At 5 years after the programme 62% of the sample received all income from social insurance. And a further 23% that were working received part of income from social insurance	Most frequent problems reported; remembering (96%), concentrating (91%), getting things done on time (86%), lack of energy (86%), making decisions (80%)	Followed vocational rehabilitation. Sweden has social insurance system which provides sickness benefit for those prevented from working by disease or injury. Time limited then assessed and if return to work considered not possible changes to a pension. Self-awareness not easily measured and no objective measure	Global return to work rates and Factors impacting and predicting return to work
Artman and McMahon (2013)	USA	Utility of self-reported functional limitations examined in relation to job maintenance for TBI who had return to work	Database	Demographic and interviews	160 TBI	Memory loss and attention/concentration limitations were the most reported. Presence of medical symptoms and emotional dysregulation (behaviour stemming from poor stress tolerance and mood lability) were reliably and inversely associated with job maintenance		Reliance on self-report, lack self-assessment skills, lack of self-awareness can influence report. Lack of data about traumatic brain injury severity	Factors impacting and predicting return to work
Power and Hershenson (2003)	USA	Investigated effects of mid-career TBI on work adjustment	Quantitative and qualitative	Interviews and questionnaires	10 TBI, 5 male, 5 female, 6 married, 1 divorced several years. Aged 25-56	Work adjustment assumes a special meaning and career development becomes a redevelopment and planning process, rather than an unbroken linear process. Many didn't seek vocational rehab until at least 1 year due to anxiety and depression affecting self-esteem. Greater pre TBI work satisfaction, greater the frustration post TBI	Self-concept linked to work adjustment and career development. TBI was a major blow to self-concept, manifest by a drop in self-image. In those with well-developed work ethic, loss of work leads to loss of one's value as a person, as well as loss of self-confidence		Factors impacting and predicting return to work and Self-awareness and adaptation

Johansson and Bernspang (2003)	Sweden	Assessed subjective life satisfaction after brain injury and its relation to work re-entry	Longitudinal study	Demographic data and questionnaires	36 participants, 24 with TBI, at 3 and 6 years after admission to rehab programme	Statistically significantly lower satisfactions at second follow up than first. At second follow up, significantly more people were satisfied with IADL in the group that had returned to work		Lack of insight to report problems. All had rehabilitation	The meaning of work, quality and life satisfaction
Kreutzer *et al.* (2003)	USA	Examined job stability variables	Mulit centre analysis TBI follow up at 1, 2, 3 and 4 years post	Medical records and interviews	186 TBI, 61% severe, 22% moderate and 17% mild. Working age 18-62 years and working pre injury	After injury 34% were stably employed, 27% unstably employed and 39% unemployed. Minority group members, those who didn't complete high school and unmarried were more likely to be unemployed	Driving independence highly influenced and significantly related to employment stability. 35% were employed at 1 year, 37% at 2 years, and 42% at 3 or 4 years. If not working at 1 year post more likely to be unemployed at 2 or 3 years	All sample had rehabilitation	Global return to work rates and Factors impacting and predicting return to work
Soeker *et al.* (2012b)	South Africa	Described perceptions and experiences of brain injury regards return to work rehabilitation programmes	Thematic content analysis	In depth interviews	9 men, one woman, moderate-mild brain injury	Two themes; enablers and barriers to return to work Participants felt that workplace adaptations enabled them to adapt to the workplace demands and that ergonomic adaptations speeded up the time they tool to do tasks	Administration delays were time consuming in the disability application process	Small sample	Factors relevant to sustaining work
Hooson *et al.* (2013)	United Kingdom	Explored experience of return to work rehabilitation with 10 TBI	IPA	Semi structured interviews	8 men, 2 women	TBI find return to work experience difficult and painful. Experience a distinct grief reaction in the process of exploring re-engagement in occupation following TBI. Excessive fatigue generated a fear of failure in attempting to engage in return to work	All participant viewed working as a means to develop as a person and to establish their identity based largely on their earning ability. Related to not having earning ability they reported a sense of loss that came with that realisation	All 10 had return to work rehabilitation. High ratio of men in sample	Factors impacting and predicting return to work and Self-awareness and adaptation
McCrimmon and Oddy (2006)	United Kingdom	Investigated the role of cognitive functioning, fatigue, mood and behaviour in return to work following moderate-severe TBI	Comparative design between subject measures		Comparisons made with 20 TBI who had returned to work and 13 who had not	Unemployed group reported significant higher levels of fatigue and depression	Mood, fatigue and behavioural problems may impede ability to return to work Subjective measures may be more superior to objective measures in predicting return to work		Factors impacting and predicting return to work
Nimgade and Costello (2003)	USA	Return to work of a company president	Description	Return to work journey	One TBI, 64 year old man	Highlights challenges during workplace rehabilitation with cognitively demanding jobs. High potential for frustration given the gap between function and job expectations	Stress management techniques important to cope with high frustration levels	Only one case	Factors impacting and predicting return to work
AMED									
Ownsworth (2010)	Australia	To descried the implementation of a metacognitive contextual approach for facilitating return to work for ABI	12 month longitudinal investigation . Descriptive case series.	16 week metacognitive intervention in community emphasised executive strategy trainings, enhancement of social factors and return to work	3 ABI, one male ABI aged 33 with brain injury, one male aged 51 with stroke, one female aged 43 with brain injury, all 3-7 years post. 3 ABI (2 RTA & 1 stroke)	Each achieved paid work within 3-16 weeks. Preliminary support re efficacy of metacognitive approach. Metacognition is an aspect of executive function which refers to self-awareness of post injury changes and the capacity to self-monitor and self-regulate behaviour during task performance. Participants achieved a work placement within 3-16 weeks following a metacognitive approach (increasing self-awareness of post injury changes, self-monitoring and self-regulating behaviour)	Involved group sessions to increase self-awareness and acquired brain injured effects and job re-entry skills	Included one CVA/stroke participant. Small sample	Self-awareness and adaptation

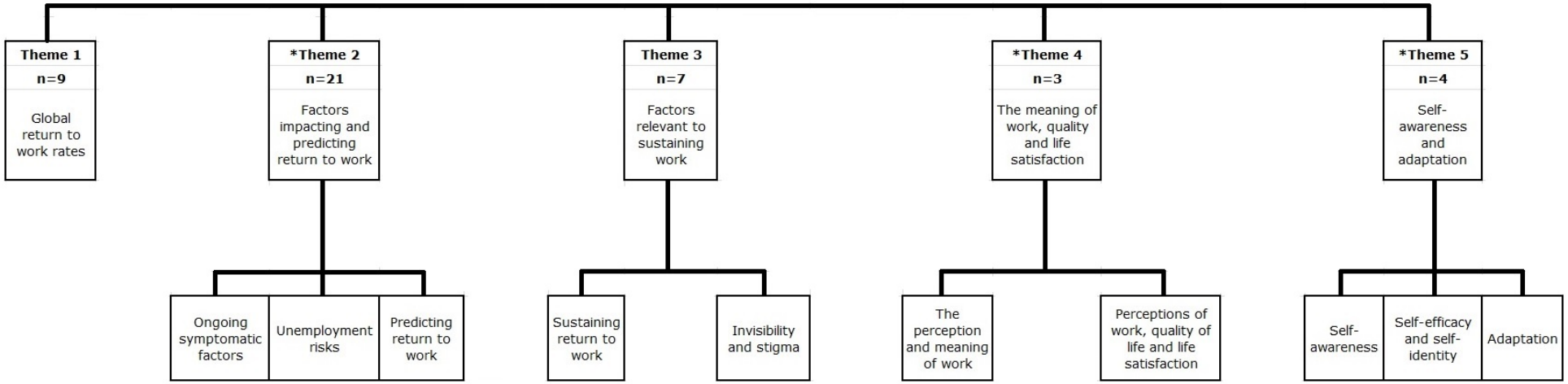
BMJ									
Schonberger et al (2011)	Australia	Created and tested a structural equation model of the prediction of functional and employment outcome post TBI	quantitative	Demographic data	949 TBI, moderate to severe, 74% males, median age 25.7 years	Age, education, pre injury employment, injury severity, and limb injuries were direct predictors of employment outcome. Gender, pre injury psychiatric disorders and limb injuries were related to employment outcome by their association with mood, cognitive and behavioural changes	Pre injury employment predicted post injury employment. Longer PTA duration affected employment. Rate of post injury unemployment (44%) was dramatically higher than their pre injury (12%)	All had rehabilitation	Factors impacting and predicting return to work
Medline									
Doctor *et al.* (2005)	USA	Examined amongst those working pre injury, the risk of unemployment 1 year after TBI relative to expected risk of unemployment	Longitudinal inception cohort	Demographics, therapy and medical records	418 mild-severe TBI	Results indicate that 42% of TBI was unemployed versus 9% expected relative risk. Risk for unemployment was higher amongst males, those with higher education, with more severe injuries and more impaired early neuropsychological or functional status	Unemployment substantially higher after TBI for those who were employed when injured. Being male, aged 25-39 and having at least a high school education associated with greater risk of unemployment	44 lost to follow up at 1 year	Factors impacting and predicting return to work
Opperman (2004)	USA	To describe the meaning ascribed to returning to work after TBI	Qualitative, multiple case study design, phenomenological themes	Semi structured interviews and written documentation	Random sample of two participants (both female, unmarried and aged 31 and 46 years) with TBI	Three themes established; experience of finding work after injury, experience of maintaining work and independence related to work	Participants subjectively and objectively define work. Societal valued individuals relate to work. One participant described work as a large part of who a person is because that is what they do day in and day out. The other participant described work objectively and as to get money to live, to get bills. Both reported multiple jobs since injury	Only two women in the sample. Both participants had vocational rehabilitation	The meaning of work, quality and life satisfaction
Science Direct									
Bonneterre *et al.* (2013)	France	Analysed a therapy programme to assist TBI in return to work and retaining their job in the ordinary work environment	Retrospective		100 TBI, aged over 18, GOS 1 or 2, 80% male, 69% under 30 years at time of injury	Factors associated with return to work success were at short term (2-3 years), the presence of significant workplace	Workplace support key factor for job retention in the medium term. The presence of mental illness/behavioural disabilities remains the main factor limiting maintaining work		Factors impacting and predicting return to work
Trip Database Plus									
Grauwmeijer *et al.* (2012)	Netherlands	Evaluated employment outcome with mod-severe TBI and identified who at risk of unemployment 3 years post injury	Prospective cohort study. Descriptive analyses	Demographics and records	113 patients agreed to take part. 94 mod-severe, TBI aged 18-65 years completed	Potential predictors included patient characteristics, injury severity, GOS functional outcome measure at hospital discharge. TBI patients with psychiatric symptoms and impaired cognitive functioning at hospital discharge are at the highest risk of long term unemployment. Employed persons were significantly younger, less often demonstrated psychiatric symptoms and were less impaired, with a shorter length of hospital stay and higher scores on the GOS	94 patients (83%) completed the 3 year follow up. Employment rate dropped from 80% pre injury to 15% at 3 months post injury and gradually increased to 55% after 3 years. Depression and anxiety are most common psychiatric problems in TBI patients	Of 113 only 94 completed	Factors impacting and predicting return to work

Web of Knowledge									
Franulic *et al.* (2004)	Chile	Evaluated patients psycho-pathological and social situations and described evolution and return to work predictors	Quantative	Outcome data	202 TBI, evaluated 2, 5 and 10 years. 71 at 2 years, 73 at 5 years and 58 at 10 years	Unemployed patients presented more severe symptoms of anxiety and depression than those who were working. Factors determining poor reinsertion to workplace are; age, low educational level, lack of job qualifications and greater cognitive impairment		Lack of GCS records limiting factor	Factors impacting and predicting return to work
Machamer *et al.* (2005)	USA	Explored stability of work experience after injury	Quantitative and demographic	Outcome data	165 TBI, mild-severe followed up 3-5 years post injury	Amount of time worked significantly related to injury severity	Once returned to work, ability to maintain uninterrupted employment largely related to pre morbid characteristics; being older, higher income before injury, or pre injury job with benefits. Participants who failed to maintain stable uninterrupted employment were younger, had lower pre injury earnings and had a pre injury job that did not provide benefits	Contained mild-severe injuries. Two thirds of sample had complicated mild TBI	Factors impacting and predicting return to work
Zetoc									
Forslund *et al.* (2013)	Norway	Described employment outcomes and assessed impact of personal and environmental factors on employment outcomes 2 years after moderate to severe TBI	Prospective cohort	Quantitative	100 moderate to severe TBI, aged 16-55, followed up at 1 and 2 years post	Personal factors include; age gender, education, work demands, marital status and child care. Environmental factors include support by friends, rehab services, well-coordinated healthcare, own transport	At 2 year follow up 44% were employed. Patients with less severe injuries, supported by friends, and driving at 1 year follow up were more likely to be employed at 2 year follow up	Scandinavian countries provide better healthcare insurance against disability, sickness and unemployment	Global return to work rates and Factors impacting and predicting return to work
Rietdijk *et al.* (2013)	Australia	Explored possible correlations between measures of functional communication skills in the first year post TBI and later employment	Observational study employing a prospective longitudinal design	Functional assessment of verbal reasoning and executive strategies, (FAVRES)	14 adults TBI	8 TBI returned to employment, 5 unemployed and 1 lost to follow up	FAVRES shows promise as an assessment that may be associated with successful employment outcome	Small sample	Factors impacting and predicting return to work
Benedictus *et al.* (2010)	Netherlands	Evaluated the cognitive and behavioural disturbances related to return to work in TBI	Longitudinal cohort study		434 TBI of various severity	Patients encountered problems in the physical (40%), cognitive (62%), behavioural (55%) and social domains (49%) of the differentiated outcome scale	Half the patients were able to resume previous vocational activities although 1 in 3 experienced cognitive or behavioural problems		Global return to work rates and Factors impacting and predicting return to work

Van der Horn *et al.* (2013)	Netherlands	Investigated the relation of post concussive complaints, anxiety and depression with vocational outcome in TBI patients of various severities and assessed sex differences	Prospective cross-sectional cohort study	Extended Glasgow Outcome Scale and other outcome measures	242 TBI of various severity	67% of TBI had complaints; 22% were anxious and 18% depressed. Frequency of complaints increased significantly with injury severity. Reports of complaints were lower with complete return to work (anxiety 9% and depression 5%). With incomplete return to work this was 42% and 37%			Factors impacting and predicting return to work
Hand search yield									
Boake *et al.* (2005)	USA	Explored employment after mild TBI including patients not admitted to hospital	Prospective study, concurrent inception cohorts	6 month follow up data	210 working age adults, mild-moderate TBI and 122 patients who sustained general trauma not involving the brain	Majority of non-hospitalised with mild TBI did not work for at least 1 month and not begin working until 1-3 months after injury. Most with moderate TBI remained unemployed at 6 months post injury	Contrary to theory that brain injury is more disabling for cognitively demanding occupations, those with higher job status tended to begin work earlier	Greater attrition in lower job status may have been underestimated lost work time	Factors impacting and predicting return to work
Petrella *et al.* (2005)	Canada	Explored understanding how intrinsic and extrinsic factors influence productive involvement over time	Interpretive research paradigm, Grounded theory methodology	Semi structured interviews	6 ABI, lived with brain injury for average of 14 years	Required; an opportunity to try, support and feedback from others, experimenting, and appraisal of themselves. Fighting for identity meant struggling to maintain a sense of self, which involved pushing a set of beliefs about themselves based on their past lives, without taking into account changes in their capacities caused by the injury	Postulates incorporating the social cognitive theory in rehabilitation and moving from a deficits approach towards a strengths model of practice. Demonstrates importance of providing self-efficacy building environments as BI is exploring their potential productive selves. Building self-efficacy, in the social cognitive theory, viewed as essential to enable important transitions that present new challenges in a life course	Small sample	Self-awareness and adaptation
Zetoc alert post initial search									
Friedland and Potts (2014)	United Kingdom	Reviewed the return to work rate for moderate to severe TBI one year post injury	Retrospectively reviewed the consecutive acute hospital TBI referrals to their ABI service	Retrospective records	90 TBI individuals	40% of the sample had returned to work at one year post injury	Findings in keeping with general outcome literature. Identified that fewer than half of the sample managed to return to work at one year	Did not study whether sample group remained at work	Global return to work rates
Waljas *et al.* (2014)	Finland	Examined factors relating to return to work following mild TBI	Inception cohort design	Questionnaires, neuropsychological testing 3-4 weeks post injury, self-report	109 participants mild TBI, 52.3% women	46.8% returned to work after one week, 59.6% after two weeks, 67% after three weeks, 70.6% after four weeks, 91.7% after two months and 97.2% after one year. Four variables were significant predictors of the number of days to return to work; age, multiple bodily injuries, intracranial abnormality at the day of injury and fatigue ratings (all $P < .001$)	Findings exceed UK for minor head injury return to work as 44% after two weeks	Self-report, not clear who returned to same job, new job, full or part time or who remained in work after 1 year	Global return to work rates and Factors impacting and predicting return to work

Appendix 6 Map of the five emergent themes from the literature review yield

(n=44; 39 non United Kingdom and 5 United Kingdom studies)



*Theme 2 shares the following overlapping literature with theme 1; Bjorkdahl (2010), Bennidictus *et al.* (2010), Kreutzer *et al.* (2003), Forslund *et al.* (2013), Waljas *et al.* (2014).

*Theme 4 shares the following overlapping literature with theme 3; Levack *et al.* (2004).

*Theme 5 shares the following overlapping literature; Soeker (2011) and Soeker *et al.* (2012a) with theme 3 and Power and Hershenson (2003) and Hooson *et al.* (2013) with theme 2.

Appendix 7 Nottingham Research Ethics Committee initial favourable opinion

NHS
National Research Ethics Service

Nottingham Research Ethics Committee 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839390 (Direct Line)
Facsimile: 0115 9123300

22 November 2010

Mrs Karen Beaulieu
Senior Lecturer
The University of Northampton
Kelmarsh Building
Park Campus
Boughton Green Road
Northampton NN2 7AL

Dear Mrs Beaulieu

Study Title: **An exploration of factors that impact the return to paid work of individuals following a brain injury**
REC reference number: **10/H0403/95**

The Research Ethics Committee reviewed the above application at the meeting held on 09 November 2010. Thank you for attending to discuss the study.

Ethical opinion

Discussion

- The Committee informed you that they felt that there are quite a few topics to discuss in the 45 minutes duration of the interviews, and questioned whether it is vital that all questions are discussed. You confirmed that it is not essential that they go through all questions. You are hoping that even one question will be a 'trigger' question prompting the participant.
- The Committee asked you to clarify why you had chosen phenomenology as your methodology for the study. You stated that the phenomenological method is new to you, but you felt it the best method to obtain a participants true lived experiences. You want to find out what works for the client group in getting back to work, as evidence suggests that there are not enough people going back into work.
- The Committee asked whether participants in the study are likely to be those you have worked with. You confirmed that you would not have worked with them.
- You were asked how practical and feasible it would be to prompt participants to try to avoid using individual's names to protect individual's identities when undertaking the interviews. You stated you would prompt them, although you could not guarantee that they would not mention any names. However, if names were mentioned, you confirmed that you would not include them in the reporting.
- The Committee asked you as to what data would be held on a home computer. You confirmed that you would not be using a home computer, but will be using the University server.

- You asked the Committee if the invitation poster which you had submitted for review at the meeting could be included in a newsletter to advertise for participants. The Committee agreed that it could if it was the exact poster that they had reviewed with no revisions.

- The Committee asked you whether the telephone contact number for yourself as detailed in the Participant Information Sheets are work contact numbers. You confirmed that they are. The Committee agreed that this was satisfactory.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

Additional conditions:-

1. The Participant Information Sheet should include an independent contact for complaints, as currently the contact person the PhD Director of Studies who is also the Academic Supervisor for this study.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Investigator CV	Karen Beaulieu	
Investigator CV		15 October 2010
Protocol	1	18 October 2010
Proposed timetable and plan of work - Appendix 1	1	18 October 2010
Diagram of the relationships between the research aim, the three research phases and how they will develop a return to paid work brain injury theoretical framework	1	18 October 2010
REC application	62622/158390/1/450	18 October 2010
Covering Letter		17 October 2010
Interview Schedules/Topic Guides	1 - data collection - Unstructured interview schedule for brain injured participants	18 October 2010
Interview Schedules/Topic Guides	1 - Data collection - unstructured interview scedule for employers with experience of brain injury return to work	18 October 2010
Interview Schedules/Topic Guides	1 - Data collection - focus group guide for employers with no experience of brain injury return to work	18 October 2010
Advertisement	1	18 October 2010
Letter of invitation to participant	1 - To request permission from relevant organisations and to request consent to collect research data	
Letter of invitation to participant	1 - Chamber of commerce recruitment letter for employers with no experience of brain injury return to work	18 October 2010
Letter of invitation to participant	1 - Invite for all participants	
Participant Information Sheet: For brain injured participants	1	18 October 2010
Participant Information Sheet: For employers with experience of brain injury return to work	1	18 October 2010
Participant Information Sheet: For employers with no experience of brian injury return to work	1	18 October 2010
Participant Consent Form	1	18 October 2010
Evidence of insurance or indemnity		09 August 2010
Referees or other scientific critique report	Email Correspondence	12 October 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0403/95	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp

Mr Robert Johnson
Acting Chair

Email: trish.wheat@nottspct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Professor Carol Phillips – University of Northampton*

Professor Jackie Campbell – Academic Supervisor

Nottingham Research Ethics Committee 1

Attendance at Committee meeting on 09 November 2010

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Walter P Bouman	Consultant Psychiatrist	Yes	
Prof Cris S Constantinescu	Professor of Neurology	Yes	
Ms H Crow	Research Midwife	Yes	
Mr Robert Johnson	Research Coordinator	Yes	
Rev Keith Lackenby	Lay member	Yes	
Mr J Merrills	Barrister / Pharmacist	Yes	
Mr Robert Oldroyd	Lay member	Yes	
Dr N Philips	General Practitioner	Yes	
Mr Ian Thompson	Lay member	Yes	
Mrs Shirley E White	Lay member	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Trish Wheat	Committee Co-ordinator

Appendix 8 Nottingham Research Ethics Committee final favourable opinion

NHS
National Research Ethics Service

Nottingham Research Ethics Committee 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839368
Facsimile: 0115 9123300

14 December 2010

Mrs Karen Beaulieu
Senior Lecturer
The University of Northampton
Kelmarsh Building, Park Campus
Boughton Green Road
NN2 7AL

Dear Mrs Beaulieu

Full title of study: **An exploration of factors that impact the return to paid work of individuals following a brain injury.**

REC reference number: **10/H0403/95**

Thank you for your email of 3rd December 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 09 November 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Information Sheet: Brain injured participants	2	03 December 2010
Participant Information Sheet: Employers with no experience of brain injury return to work	2	03 December 2010
Participant Information Sheet: Employers with experience of brain injury return to work	2	03 December 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

10/H0403/95 **Please quote this number on all correspondence**

Yours sincerely

Miss Heather Harrison
Assistant Co-ordinator

E-mail: heather.harrison@nottspct.nhs.uk
Copy to: *Sponsor - Professor Carol Phillips*

Appendix 9 Brain injured participant information sheet

THE UNIVERSITY OF NORTHAMPTON
School of Health

Participant information sheet for brain injured participants

PARTICIPANT INFORMATION SHEET

Part 1: Information Sheet

Study Title: An exploration of factors that impact the return to paid work of individuals following a brain injury.

Invitation: I am inviting you to take part in a research study I am undertaking as part of my PhD. Before you decide whether or not to take part, it is important for you to understand what is involved. Please take the time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to contact myself if there is anything that is not clear or if you would like further information.

What is the purpose of the study? The study forms part of my PhD qualification and the School of Health at the University of Northampton is sponsoring the research. The purpose of the study is to talk to individuals who have had a brain injury and who have experienced returning to paid work in order to find out about their experiences.

Do I have to take part? Participation is entirely voluntary, so you do not have to take part. If after consideration, you do wish to take part, this decision will not effect the care or support you may currently receive. If you decide to participate, you are free to change your mind at any time, without giving a reason.

What happens if I agree to take part? If you decide to take part, you will be asked to sign a consent form and return it to me in the pre paid envelope provided. On receipt of the consent form I will arrange to meet with you at a mutually convenient time and place. I will ask you questions about your return to paid work experiences and the interview will last around 45 minutes but will depend on how much you want to say. You can choose to end the interview at any time. There are no right or wrong answers; it is your views that are important. The interview will be audio taped so that I can accurately record the information provided.

What are the potential benefits of taking part? You are unlikely to receive any direct benefit from participating in the study, but it is anticipated that the findings will assist in informing clinicians about brain injured individuals return to paid work experiences.

What are the possible disadvantages and risks I should know about before I take part? I do appreciate that it may be difficult to discuss certain topics or negative experiences. Please feel assured that you would be able to decline answering any questions. Also, you are free to ask me to rephrase any of the questions I ask you.

What happens if something goes wrong? If you have a concern about any aspect of this study, you should speak to the researcher, Karen Beaulieu, telephone 01604-892876 or the research supervisor, Dr Jackie

Parkes, telephone 01604-892720. If you are not satisfied with this, you can contact Professor Carol Phillips, Associate Dean for Knowledge Transfer and Development, telephone 01604-892309 regarding how to make a complaint.

If the information in Part 1 has interested you and you are considering taking part, please continue to read the additional information in Part 2 before making any decision.

Part 2: Additional information

Will the information I provide be kept confidential? Yes, all information about your participation in this study will be confidential. The information you provide is only for use in this study and will not be given to any other party. You will be given a pseudonym in order to protect your identity. The taped interview will be heard and transcribed only by myself. The computer will be password protected so that only I can access it. The tape and interview transcript will be stored in a locked cabinet to ensure confidentiality. This information will be destroyed five years after the research is completed.

The only time when I would be required to break confidentiality would be if you disclosed information that suggested that there was an immediate risk to you or someone else. In such circumstances, I would discuss this with someone who could help for example Headway or another agency but will only do so with your full knowledge.

In order to protect the identity of employers involved in your return to work experience, I would appreciate if you could try not to mention specific names during the interview.

What will happen to the results of this study? The results will be written up as a PhD thesis that will be submitted to the University of Northampton as part of their PhD requirements. The results may also be published in a relevant journal. When completing the consent form you will be asked if you would like to receive a research summary.

Who has reviewed the study? The following supervisory team at the University of Northampton; Professor Jackie Campbell, Professor Annie Turner and Dr Jackie Parkes has reviewed the study. Ethical approval has been provided from the Research Ethics Committee at the University of Northampton and Nottingham Research Ethics Committee 1.

The University of Northampton's Combined Liability Insurance Policy provides indemnity for students of the institution carrying out research work as part of their award.

What happens next? If you wish to participate, we can organise a time to meet. Please contact me by e mail or phone and I will send you a pre paid, addressed envelope so you may return a signed copy of your consent form.

THE UNIVERSITY OF NORTHAMPTON
School of Health

Thank you for taking the time to read this information sheet and considering participating in this study.

Karen Beaulieu
K206
Park Campus
The University of Northampton
Boughton Green Road
Northampton
NN2 7AL
karen.beaulieu@northampton.ac.uk
Tel 01604 892876 or 07702 040037

Appendix 10 Employer participant information sheet

THE UNIVERSITY OF NORTHAMPTON
School of Health

Participant information sheet for employers with experience of brain injury return to work

PARTICIPANT INFORMATION SHEET

Part 1: Information Sheet

Study Title: An exploration of factors that impact the return to paid work of individuals following a brain injury.

Invitation: I am inviting you to take part in a research study I am undertaking as part of my PhD. Before you decide whether or not to take part, it is important for you to understand what is involved. Please take the time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to contact myself if there is anything that is not clear or if you would like further information.

What is the purpose of the study? The study forms part of my PhD qualification and the School of Health at the University of Northampton is sponsoring the research. The purpose of the study is to talk to employers and find out about their experiences of supporting individuals who have had a brain injury when they have returned to paid work.

Do I have to take part? Participation is entirely voluntary, so you do not have to take part. If you decide to participate, you are free to change your mind at any time, without giving a reason.

What happens if I agree to take part? If you decide to take part, you will be asked to sign a consent form and return it to me in the pre paid envelope provided. On receipt of the consent form I will arrange to meet with you at a mutually convenient time and place. I will ask you questions about your experiences of helping an employee or employees to return to paid work after a brain injury and the interview will last around 45 minutes but will depend on how much you want to say. You can choose to end the interview at any time. There are no right or wrong answers; it is your views that are important. The interview will be audio taped so that I can accurately record the information provided.

What are the potential benefits of taking part? You are unlikely to receive any direct benefit from participating in the study, but it is anticipated that the findings will assist in informing clinicians about brain-injured individuals and their employer's return to paid work experiences.

What are the possible disadvantages and risks I should know about before I take part? I do appreciate that it may be difficult to discuss certain topics or negative experiences. Please feel assured that you would be able to decline answering any questions. Also, you are free to ask me to rephrase any of the questions I ask you.

What happens if something goes wrong? If you have a concern about any aspect of this study, you should speak to the researcher, Karen Beaulieu, telephone 01604-892876 or the research supervisor, Dr Jackie

Main switchboard 01604 735500
Study enquiries [illegible]
Study email study@northampton.ac.uk
Web www.northampton.ac.uk

Park Campus
Boughton Green Road
Northampton
NN2 7AL

Avenue Campus
St George's Avenue
Northampton
NN2 6JD

Parkes, telephone 01604-892720. If you are not satisfied with this, you can contact Professor Carol Phillips, Associate Dean for Knowledge Transfer and Development, telephone 01604-892309 regarding how to make a complaint.

If the information in Part 1 has interested you and you are considering taking part, please continue to read the additional information in Part 2 before making any decision.

Part 2: Additional information

Will the information I provide be kept confidential? Yes, all information about your participation in this study will be confidential. The information you provide is only for use in this study and will not be given to any other party. You will be given a pseudonym in order to protect your identity. The taped interview will be heard and transcribed only by myself. The computer will be password protected so that only I can access it. The tape and interview transcript will be stored in a locked cabinet to ensure confidentiality. This information will be destroyed five years after the research is completed.

The only time when I would be required to break confidentiality would be if you disclosed information that suggested that there was an immediate risk to you or someone else. In such circumstances, I would discuss this with someone who could help for example the relevant Job Centre Disability Employment Advisor or another agency but will only do so with your full knowledge.

In order to protect the identity of the brain injured individual(s) involved in your return to work experience, I would appreciate if you could try not to mention specific names during the interview.

What will happen to the results of this study? The results will be written up as a PhD thesis that will be submitted to the University of Northampton as part of their PhD requirements. The results may also be published in a relevant journal. When completing the consent form you will be asked if you would like to receive a research summary.

Who has reviewed the study? The following supervisory team at the University of Northampton; Professor Jackie Campbell, Professor Annie Turner and Dr Jackie Parkes has reviewed the study. Ethical approval has been provided from the Research Ethics Committee at the University of Northampton and Nottingham Research Ethics Committee 1.

The University of Northampton's Combined Liability Insurance Policy provides indemnity for students of the institution carrying out research work as part of their award.

What happens next? If you wish to participate, we can organise a time to meet. Please contact me by e mail or phone and I will send you a pre paid, addressed envelope so you may return a signed copy of your consent form.

Main switchboard 01604 735500
Study enquiries 0800 358 2235
Study email study@northampton.ac.uk
Web www.northampton.ac.uk

Park Campus
Boughton Green Road
Northampton
NN2 7AL

Avenue Campus
St George's Avenue
Northampton
NN2 6JD

THE UNIVERSITY OF NORTHAMPTON
School of Health

Thank you for taking the time to read this information sheet and considering participating in this study.

Karen Beaulieu
K206
Park Campus
The University of Northampton
Boughton Green Road
Northampton
NN2 7AL
karen.beaulieu@northampton.ac.uk
Tel 01604 892876 or 07702 040037

Appendix 11 Participant consent form

THE UNIVERSITY OF NORTHAMPTON
School of Health

Consent Form

For Participating in the Study of:
An exploration of factors that impact the return to paid work of individuals following a brain injury.

Details of the research can be found in the attached participant information sheet.

Please initial box Y/N

I confirm that I have read and understood the participant information sheet. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that the information I disclose will remain confidential and that my data will be destroyed after five years. ☐

I understand that I can withdraw my participation at any time with no explanation required, and that this will have no effect on any current or future services. ☐

I agree that when discussing experiences I will try to avoid using individual's names. ☐

I consent to my discussion being audio taped, typed, stored electronically and non identifiable quotations potentially being used by the researcher in subsequent publications. ☐

I understand that relevant sections of my data collected during the study may be looked at by individuals from Headway, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

Confidentiality and data protection
All data will be kept in a locked cabinet in the principal investigators office. All information will be kept on password-protected computers. This non-personalised data will be coded so that it cannot be linked to an individual.

I give consent to take part in this study ☐

Main switchboard 01604 735500
Study enquiries 0800 352 2232
Study email study@northampton.ac.uk
Web www.northampton.ac.uk

Park Campus
Boughton Green Road
Northampton
NN2 7AL

Avenue Campus
St George's Avenue
Northampton
NN2 6JD

THE UNIVERSITY OF NORTHAMPTON
School of Health

I would like to receive a copy of the research summary ☐

Printed name of participant: .....

Participant's signature: ..... Date: .....

Printed name of researcher: .....

Researcher's signature: ..... Date: .....

Please complete and tick the box of your preferred choice of contact

Contact address: ..... ☐

.....

.....

Contact phone number: ..... ☐

Contact e-mail address: ..... ☐

Please e mail or phone me and I will send you a pre paid, addressed envelope to return a signed copy of your consent form – thank you!

E mail karen.beaulieu@northampton.ac.uk
Tel 07702 040037 or 01604 892876

Appendix 12 Phase one demographic summary

P	Sex	Age	Marital status	Type of BI	Time since injury & age at injury	Time in rehab	Type of rehab	Vocat rehab?	Previous job	Education	Hobbies pre BI	Accom before BI	Current job	Economic climate on return	Symptoms	Hobbies post BI	Accom since BI
1	m	52	m	ABI	18/3/98, 39 yrs	12 months	Acute team	no	Sales manager, global banking	Finance degree	Piano, photography, DIY	same	retired	+ve	Poor vision	Same except piano	same
2	m	41	m	TBI	5/1/90, 20yrs	1 month	Acute team	no	3; office, factory & grass cutter	gcse	Playing football	Alone in bedsit	Post room assistant	+ve	Word finding, epilepsy, fatigue, S&L, memory	Computers, family	House, wife & children
3	m	49	m	ABI	2007, 44 years	24 months	acute	no	Self-employed builder	gcse	swimming	house	unemployed	-ve	Poor vision, L & R weakness, memory, attention	Talking books	Same with stair lift
4	m	49	div	ABI	1982, 21 yrs	1 week	acute	no	Royal navy	gcse	Any sport	With parents	cleaner	+ve	Attention, new learning	badminton	Alone in house
5	m	36	s	ABI	2000, 26 yrs	6 months	acute	no	weed sprayer	gcse	music	Shared house	Street cleaner	+ve	memory	music	Lives alone, flat
6	f	47	m	ABI	2004, 40yrs	3 months	acute	no	PA	Chemistry degree	badminton	Lived with mum	unemployed	+ve	Writing, reading & talking	Headway	House with family
7	m	48	div	TBI	1980, 17yrs	3 months	acute	OT workshop	Apprentice maintenance engineer	gcse	motorbikes	Lived in own house	Handyman	-ve	Fatigue, memory, withdrawn	motorbikes	Own home
8	f	63	div	ABI	2002, 54 yrs	18 months	acute	no	Accounts administrator	gcse	Badminton, going out	same	unemployed	-ve	Poor smell, taste, vision & hearing	same	Own house
9	m	35	m	TBI	29/7/94, 19 yrs	6 weeks	acute	no	college	btec	Photography, drugs	With parents	Support worker	+ve	Weakness r, memory, fatigue	Music, computers	With wife in house
10	f	54	partner	ABI	24/3/10,	1 month	acute	no	3; sales,	gcse	Gardening,	same	Unemployed	+ve	Memory,	Headway	Same

					53 yrs				property, wellness clinic		antiques				planning, attention, fatigue		house
11	m	61	s	ABI	1999, 49 yrs	3 months	acute	OT computer	Chief clerk, railway	gcse	Walking, gym	house	Admin assistant	+ve	Temper, odd sense of humour, epilepsy	walking	Lives in flat
12	m	31	engaged	ABI	2008, 29 yrs	1 month	acute	no	Self-employed builder	BSc computing	Snow boarding	Shared house	School care taker	-ve	Memory, blind in 1 eye, can't drive, fatigue	reading	Lives with fiancé in house
13	f	42	m	TBI	2005, 36 years	12 months	Acute & med	no	Parish clerk	BSc bio sciences	Ran guides, age concern volunteer, gym	cottage	Teaching assistant	+ve	Memory, anger, attention, noise intolerance, fatigue	same	same
14	m	52	m	ABI	1999, 40 yrs	3 months	Acute & med	no	Train driver	Left 16 no gcses	Work & Walking dog	house	Train cleaner	+ve	Speech, memory,	fishing	same
15	f	47	s	TBI	2008, 45 yrs	none	none	no	Self employed	Fine art foundation course	Work & product design	house	Territorial army	+ve	Poor vision, speech, weakness r, headaches, noise intolerance, memory	Guitar but difficulty	same
16	f	31	div	ABI	1998, 18 yrs	8 weeks	acute	Disability resource centre	Travel agent	gcses	Going out, aerobics	With mum and dad	telesales	+ve	Memory, decision making, organizational skills	same	Had house but back with parents

Appendix 13 Phase one anonymous participant transcript

R=researcher

P=participant

R

Can you to tell me as much about your experience of return to paid work as you can? I really want to hear about your whole experience, in particular highlighting any barriers and success factors that you experienced

P

Mmm OK

R

Perhaps starting from when you had your haemorrhage, what happened in terms of your experience returning and then things that helped or didn't help along the way?

P

Ok, from the day I had the haemorrhage I worked at X at the time and they were fantastic and my line manager was a good friend of mine and he was a very good link back to the X at that time, not that I particularly cared less about the X at that stage as I was more worried about naturally getting back to some sort of form of health. As we neared it I knew fairly soon em that I was out of it for nearly 5 weeks and when I woke up I could have if needed have a year off work and the X was going to be very supportive so I had a lot of positive messages about don't worry, we'll support you and that was a huge encouragement. Em, the X has got an occupational health department and they were involved and an absolutely amazing woman that again has grown to become a very good friend of mine em she offered lots of encouragement so tips and hints for example she said it's going to be helpful to start meeting your colleagues before you go back to work so what about organising a coffee with some colleagues and just talk about nothing else but forget work just to get back into them seeing you and you seeing them so we organised a few of those and my wife came with me as I wasn't very good and couldn't walk very well at the time and had a walking stick. That was really helpful em then as the day approached there were more warnings I suppose from occupational health that the people's reactions to me might not be particularly encouraging and she said there are some people who are not going to know what to say to you so rather than say the wrong thing they will not say anything at all, and for you it is going to feel like they are totally ignoring you and that is exactly what happened. Em I then returned to work and some people actually walked away when they saw me coming and that felt

incredibly hurtful but I again just thought about it and thought ok that's because they can't deal with this but others were very very welcoming and made me feel better. The big problem for me was a lot of the people had changed as it was a year on and quite a few that I had worked with had changed, moved on, new people had come in so going back I genuinely felt like the new boy again.

R

Yes, can I ask at what point you returned to paid work, you said you had this connection with occupational health?

P

X was the day I returned to paid work.

R

So that was a year since your illness?

P

That was 3 days off a year.

R

So you had been away from work completely and then you had contact with the occupational health lady who had helped you.

P

Yes that was leading up, perhaps 3 months before but I returned to work on X so from say from the beginning of the year from X I started the coffee time contact as I called it and em then my first day back was X

R

Can you tell me how the process then worked?

P

Em, well I just again worked with my line manager and to some extent I had to relearn the job cause I had been through such a horrendous experience and I had been out for so long I had forgotten how to sort of maintain a X and I didn't really know when returned what my future role was going to be because even I could see that it was going to take a long time to get back, so what did I do in the interim? So I discussed that with my line manager and he was incredible, he was really helpful, encouraging and we just worked out that I was only going to be there half a day each fortnight so there isn't a lot you can do so he suggested that I read some things so

that I could work my way through those so next time I went in we would have a chat and he would update me on what he thought I needed to know and so we just kept doing it like that until I was more or less back up to speed in terms of my hours. Em then he said look at any point you feel you need to stop or feel need to go home as the worst thing for me at that time was fatigue, I was terribly terribly fatigued again that was from going from sleeping 20 hours per day when it first happened down to about 12 hours a day when I returned to work but again I was warned that as soon as returned to work that the fatigue was going to get worse again and so I went from my first day and I think I slept for about 16 hours I was just exhausted it was just going into work on the train and doing all of that it sounds pathetic but it was just such a huge load being put back on my brain, you know my brain was working ten times as hard as it had been for the previous year or so, so it was a very gradual thing, line manager as extremely good and we just worked at it like that and em there were some things I needed help with and again occupational health discussed access to work scheme. I'm not sure that it is still running but it was superb. They had like a workplace assessment and within say the first 4-6 weeks they had someone come from the access to work team for my area and did an assessment and said that he would refer me on to the Royal National Institute for the Blind (RNIB) cause of my eyesight still not being great so the RNIB came out and did an assessment. They came up with a scheme of work that would assist me so things like voice recognition software which was a god sent cause like having Parinaud's syndrome (and I still have it) so close working was difficult so if I could keep my head fixed in one place I could read much better so voice recognition software helped as I just had to look at the screen and talk so I had a massive screen and if I needed to read anything I could set up a vertical camera so I just slid what I wanted to read under this camera and it came up on my screen and I could even adjust the size of the font and colour so we found that black on yellow was better form me and a certain font size em so all of those sort of things were incredibly helpful and that was all through occupational health so that was all set up and they also set it all up for me at home so if I felt that I wanted to read or do things at home I could use the laptop that the X provided and had a desk and same vertical camera set up at home that the X provided , so all I had to do was take my laptop from home to work and I had the same situation replicated. Em and that made me feel that I was going to get back into work much more quickly and also that I felt like there was a huge amount of commitment to help me to do that.

R

Yes, going back to when you went back to work very gradually can you take me through how gradually?

P

It was for 4 hours, 10-2pm so a half day and then I didn't go back again for 2 weeks so a half day each fortnight to start with and that was for weeks and weeks and then it moved to 2 half days per fortnight and that was for weeks then 3, 4 & 5 but still only half days and then the next phase was to lengthen the days so say 5 then 6 hours for so many weeks so it was very gradual, The worst thing for me was the fatigue as it was just unbelievable. I would not have felt that it could have worsened any more but it did and again I had been warned that this would happen, so does that answer your question?

R

Yes it does. How long was it before you get back to working full time?

P

Yes I did and I think it was 18 months roughly before I worked full time. It was a very gentle em, the occupational health manager had had some experience em with ABI so she was very familiar with the problems of fatigue and short term memory, my memory had improved but it still needed some work and I had had speech therapy to help with talking and so on and of course talking an trying to communicate was a big part of my job, so trying to X I needed to be able to communicate that really well and probably day 1 it would have been impossible. There was no way that I could have gone back full time from day 1.

R

You mentioned about getting to work did you commute on the train?

P

Yes, em, it was about 1 hour and 20 minutes one-way and that was on top of working as well.

R

Did you notice any impact of that?

P

That's a good question cause the one thing I noticed about the travelling was about how at first I just couldn't stand so many people, the crowds were just, I couldn't believe that there were so many people yet I had done this for years and then all of a sudden I thought where have they all come from and I can remember that feeling. It was really weird and it upset me a bit thinking about how I found it weird as I had done it for years and yet when I get back on the train I noticed it. The first time was ok as it was 10am I started and then when I left at 2pm it was quieter so I would avoid the busy times but when I started to get into the busier times I found it really unnerving at the number of people and that took me months to get accustomed to again.

R

Did you work out why?

P

Em well I think it was because I had spent so much time with fewer people. I was never on my own from the day I had the haemorrhage to this day practically. I have never been on my own so it's not as if I haven't had any human contact but it is this issue of volume, I think coming out of a very peaceful and quiet environment and background for some considerable time and em to suddenly, I think it was almost cause I felt that I deserved more sympathy and of course they didn't care cause they don't know so I think I was using a walking stick and that, I think people treated me differently cause I had that and in a way I thought that was a positive thing but I did need it as I was a bit unsteady , and I used it for some time.

R

You said there that you got used to the quiet, do you think it was anything to do with the noise or volume on the train?

P

That was probably part of it em yes because here now it is quiet but on the train it is noisy and I think the other thing was, this is going to sound terrible but I was used to being the centre of attention in many ways as the ill person so people were coming to see the ill person, I was being treated so all of a sudden I am back with thousands of people not one of which could have given 2 hoots about me and so it was that ok I have to get used to that again. I wasn't looking for attention but I was just thinking I

had always been the subject of attention and suddenly there was none at all and probably part of it.

R

Thinking about what actually helped you to return to work; you have told me a lot about the positive experiences, is there anything else that helped?

P

My wife, family and friends helped me. There was never a doubt on my mind that I was going to go back to work, I was never going to look for medical retirement although it was discussed, mentioned once, what about it? I said no absolutely not, I'm coming back and that's it.

R

So did this belief that you were definitely going back to work come from you?

P

Yes from me, absolutely and once I made that clear that is when everybody supported and said this is what I'm going to do so whatever you are going to do has got to help me achieve - I didn't say it in those terms but that was the general sort of context I think.

R

So do you think that helped you on your journey back?

P

Yes, having a positive wife, my wife doesn't do negative she is very positive, glass half full never half empty. Em there were a few days when I had a few black days but other than that it was always onward sand upwards and it was difficult being back at work as it was something I had been very good at and suddenly it was no longer within my grasp and that was immensely frustrating and I 've often em referred to it as a huge game of snakes and ladders em so I was on a ladder trying to get back up but because I have had so many different surgeries I would slide back down the snake again and have to start again and I've found that immensely frustrating and there was no other way of dealing with it really.

R

That is the reality I guess?

P

Yes in my mind it was yes do this or you will have to retire and for me I was 39 and I thought I couldn't retire at 39. That is just impossible. I was back at home and I thought retire at 39 that is just not me. I'm retired now at 51 but I managed a few years - 11 years later but I had come to the end of the road, as by 51 I just couldn't keep doing it.

R

Where there any things that were difficult or that didn't help?

P

People's attitudes to me definitely, that really bugged me I felt that quite hurtful.

R

Can you tell me more about that?

P

Em, this I don't know what to say so I'll walk away. I don't' want to upset you so I'll walk away. Hang on a minute people actually saw me coming and they would pick the phone up so I couldn't talk to them and I could see them doing it and that felt hugely, I felt really hurt. I guess you toughen up and it happens either I stopped noticing or they stopped doing it can't remember which em but after a while you just move on and those things aren't an issue. When I first went back again it is this whole idea of having a huge amount of support and attention and then all that was gone and people were ignoring me and I found that particularly negative, the attitude of certain senior managers I felt difficult at times because they had assumed that I would be incapable of doing anything em and I thought that was very ignorant on their part and again this woman in occupational health actually spoke with one of those managers to put them straight but the biggest thing for me and in a way this is why I retired was having to start again after each illness that just got to me in the end and I thought I just can't do this anymore. I cannot go back again and start again. If I was working on a project That wasn't going to stand still for me so when I got back someone else had finished it or I did something else that was hugely negative but there was no way around that and X couldn't say well we will forget that you have this whole range of X you have to X it and we'll just wait until you feel better so I felt guilty that I was letting the side down but I got out of that because it wasn't my fault. Someone once sat me down and I can't remember who it was but they used that phrase "this isn't your fault, so stop feeling like that" I thought yeh it was like someone gave me permission to think a different way and that was the really only negative things the travelling, the certain attitudes but it was having to start again

every time I went back and there have been a lot of those as this is now my 8th shunt operation. Then it's fatigue, eye problems, it was never as bad as the first time but it is a mini version, weeks, months off but again learning to do it over and over again. I think X I had 4 operations so I had a shunt, gamma knife procedure, an abscess and my appendix removed then an ankle operation so I was hardly at work that year so yeh it's on top of having the shunt in place.

R

So the phased return was positive and the only negative area was people's reactions?

P

The practical difficulties were all dealt with by the access to work and the workplace assessment. Again I felt really supported by the X Access to work I think paid for 90% of the cost of the equipment back in X was £49,000 and the X paid the balance so when I saw those figures I saw the huge investment and this helped me focus. I still have some short-term memory difficulties but the more I worked or the harder I worked the better it got. Those are the negative things. All the negative things could be dealt with except the snakes and ladders complications. People's attitudes changed. I used to travel a lot for the X as I was on the X team so of course someone else needed to do that and I felt that it was the part I most enjoyed em and I didn't travel again for the X for some years so it as all the UK stuff.

R

So a change for you?

P

Yes it was and I felt, I knew it was the right thing but it felt, it didn't feel great as it was like a huge part and I had run the X so to have that removed from me was that side of the job it made perfect sense but it didn't feel right, and I loved it.

R

In terms of sustaining work was there anything that helped? As you stayed in this job for approx. 11 years?

P

Em, I was in that job 12 years.

R

So how did you sustain that job?

P

Gosh, em I think for me it was a determination that I wanted to get back to what I was before and that was my primary goal to get back to what I did before and I think I was kidding myself for most of the time cause I don't think there was ever a chance to get back to that level of seniority well in terms of grade but in terms of responsibility I never got there for some time, em, certainly X I never got back to the height that I had before. When I left I did get some very successful quite senior jobs em but em for one reason and another I never really settled again after that.

R

It sounds like you wanted to be a success, and you made it a success, is there anything else you can think of?

P

Em I think the job helped as it was for me it was getting back to the sense of the familiar which was comforting cause so much had changed err I was craving something that had stayed the same so getting back to dealing with X clients going to visit them in their countries and that sort of thing was what I wanted to get back to as it was a huge part of the job and something I really enjoyed em, I was absolutely motivated and that was one of my major goals in my head. I said to myself once I can do that I 'm back, I'm back to work and where I was but I can't remember when I travelled for the first time, I didn't go on my own. Em, gosh it may have been 5 years from the time of my illness. My first trip was to Scandinavia and that was with my then boss, we had a great trip and very successful, one of the big contracts, X, income it was great and he was a great guy to travel with and I had a great memory until the day I die of the feeling of goal achieved and the fact that not just the sheer mechanical of getting on a plane and travelling but actually go and be successful. The sense of relief when I achieved that, as well as of elation of achieving that goal. I worked hard but it was something I had to do so it was s relief when I did and I wanted to congratulate myself.

R

It sounds like the perception of your job was very much part of who you were?

P

Yes, that is accurate, spot on, cause it felt like I was almost made whole again and that had taken a long time afterwards, took me 2 and a half years to get back full time so it may have been another couple of years after that so maybe 5 years to travel again and was a massive journey perhaps 10 times that length. The relief was great.

R

It sounds like a lot of staying in that job came from you?

P

Em, I think so, nobody said you must come back it was in my mind that I was going to go back and do that job. I don't know if I was being stupid or just crazy but the idea that I was getting back to do it was going to be my measure em and that was it. There were some days that I felt I had made the wrong decision definitely but yeh just the drive to go back and do it and be successful because I was looking at the job as a big part of who I was and I think people do recognise, a bit big headed but I wanted the recognition em for having that job in the X and that level of seniority that was important to me perhaps less after the illness but I think that getting back to doing a large degree of hat I did before was important. I was in that job and variations of it in that department to 2006 then I lost my job and had a variety of jobs after that.

R

One final question – could you have sustained work if you had gone back to a different job?

P

Absolutely, if it had been a new job I would have failed. Definitely without any question I knew a large part of the job. It was suggested that I do something entirely different but I said no as it would be more stressful going into a job where I had to learn from scratch to a team and people I didn't know. They didn't see it at first bit I did and refused. It was the sense of the familiar and that is what I wanted and I found that comforting cause I did have a crisis of confidence because of what had happened and I didn't feel that or whether I would have the skills to do something new so in my previous successful job I had a lot of successful experience. In a different job or department I think I would have crumbled. One guy who knew nothing about what had happened just looked upon me as a broken piece of equipment, and thought just let's get rid of you and that's when occupational health stepped in and read him the riot act. Stop being ignorant basically and I had a meeting with this chap and I wrote down practically every word he said to me and then every point he made I and occupational health refuted. I had to do a bit of fighting and that made me mad but I think that helped me in some way the fact that I was so and helped me get through that. I thought I've fought enough to get here I'm not having him destroy that. He was just; his attitude was just pig ignorant. He was ok once we had spoken to him after that.

R

How did it feel when you got to a point when you were back at work and you knew you were back doing the job you wanted to do?

P

I felt very proud of myself actually and everybody that had helped me. I was always a very forthcoming and I hoped people would see that but I was proud of myself and my GP em he admitted that he never thought I'd return to work let alone return to the X as he had seen me at my very worst em and he thought there was no way I would go back. He told me that some years later. That helped me as I could have deluded myself that I had done well but my GP who I respected said I had made a phenomenal recovery so I felt proud but I've been very lucky – so not sure which was most.

R

Was returning to work the end of your rehab?

P

Em the only thing I thought was just getting back and getting back as big a percentage of what I did before so once I travelled again and won some X for me after that it felt like I had come home and achieved everything I wanted to and the and game and just wanted more of the same.

R

What have you done since the job you returned to after your illness?

P

I lost that job in 2006 after a reengineering of departments and I had to apply for my own job and didn't get it. I often wondered if it was because I had had so much illness whether that was a factor or hidden – and I'll never know the answer. I've had other jobs I was off for some time trying to find another job and ended up with quite a senior role, X and I was lucky to get it through networking. That lasted approx. 18 months and I left there again another reengineering so it changed and I was fed up with the travelling and a local job came up so I took it as a X and I hated it, the worst decision of my career, so that was 6 months then a job back in X and was for the X and did that and enjoyed it but unfortunately I still kept being ill then on the last day I worked in 2009 went to hospital ended up having a new shunt which only lasted 24 hours and needed a 2nd one, I knew after that I wouldn't go back and I knew I couldn't do it again em the snakes and ladders as I felt so ill so I spoke to my boss who was terrific and he supported me and occupational health same person still in

the same role knew me and was amazing and the X agreed and interviewed me and they said I deserved medical retirement and awarded me medical retirement from 2009. There have been huge highs and lows the thing that did me in the end was the struggle to start over yet again and I wasn't up for it but I often wonder if I stayed in my original job I went to back to as I think I would still be there as I love that job and the environment and had a great X and a good X – I'll never know. I've been unlucky with the illness but amazingly lucky with the help I've had, and it has made me a different person.

R

What an amazing story to set that target, achieve it and sustain it its incredible.

P

I've never thought of myself as driven but I was this time after I was ill I didn't want to be seen as disabled and I'm not having a view on others who are but I didn't want to be and I refused to be registered as disabled. Didn't see myself - perhaps it's a state of mind you either see yourself as disabled or not and I'm not cause once you are labelled there will be a different reaction to me. The X had disabled employee meetings so you could go along. I went along and felt a fraud compared to the others so I only went to one as I couldn't see myself as disabled a I'm not and was never disabled. Looking back I must have been driven to have done it. Before I thought being driven was negative but not now maybe just very motivated, always wanted to do a good job, be professional, to be popular and respected and I think I achieved that. When I left X I had some lovely comments and I'll keep them forever.

R

Is there anything else you want to say?

P

No, only the whole experience has made me hopefully a better person and I will now walk towards someone who has a problem not walk away as I remember how that felt. The whole experience has made me much more emotional and more in touch with my emotions and I see that as a good thing.

R

Thank you.

Appendix 14 Phase two employer demographic summary

Part number	Sex of employee	Approx. age of employee	Type of BI	Time since BI approx.	Age of employee at injury	Time away from work	Had employee had rehab?	If so type of rehab?	Vocational rehab?	Type of educational experience?	Type of job returned to?	Economic climate on return	Size/type of company/organisation
1	F	50	ABI	4.5 months	50	4.5 months	No	N/A	No	O levels	Admin assist	Hard	Large public service
2	M	33	TBI	13 years	20	13 years	Yes	Headway	Had assess & placed in job placement for 6 weeks	Senior school	Postman	Hard	Large public org
3	M	33	TBI	13 years	20	13 years	Yes	Headway	Had assess & placed in job placement for 6 weeks	Senior school	Postman	Hard	Large public org
4	M	41	ABI	1 year	40	1 year	No	N/A	No	Degree	Financial commercial manager	Not too bad	Large banking business
5	M	38	ABI	5 years	33	3.5 years	Yes	ABI comm. team	No	GCSE	Learning assistant	Not too bad	Small Primary School
6	M	41	TBI	6 years	35	12 months	Yes	CBT/counselling	No	Degree & PGCTE	Teacher & Head	Ok	Large secondary school

											of Year		
7	M	60	TBI	3 months	60	3 months	No	N/A	No	School/none	Manufacturer of wood doors	Facing redundancy	Private business 300 employees
8	M	55	ABI	11 months	54	6 months	Yes	General	No	Degree	IT consultant	Ok	Global business
9	M	50	ABI	2 years	48	5.5 months	Yes	Neuro psych	No	Apprenticeship	IT support analyst	Ok	Global business
10	M	50	TBI	15 years	35	10 years	Yes	Orthop	No	GCSE	Minibus driver	Hard	National charity
11	M	49	TBI	17 years	32	3 months	Yes	Physio only	No	Engineering apprenticeship	F1 driver & trainer	Hard	Self employed

Appendix 15 Phase two participant anonymous transcript

R=researcher
E=employer

R Thanks again for allowing me to come and interview you. Now, can you tell me about your experience of helping an employee following a brain injury to return to paid work and along the way if you can highlight any barriers that happened or success factors that you think were experienced?

E Right, well firstly we were contacted by the occupational health team and, you know, encouraged to sort of have meetings with them, with the affected person, myself as the affected person's manager and also the company's human resources manager…

R Yeah.

E Yeah. And you know we had those meetings, you know, regularly sort of like once a month we would all meet together at the affected person's house, you know, obviously to save him from having too much stress, etc. And those meetings were designed to, you know, to try and understand what the company's policy was on helping people come back, you know, into work after such an injury, assessing verbally as well what we felt X was capable of, understanding the, you know the types of problems he perceived he was having and how that made him feel and you know, so sort of trying to balance human elements as well as you know, not just talk from a X point of view, you know, trying to balance both of those aspects together. Of course the human resources man, he well you know was there, you know in the capacity as well of, you know, understand, helping the affected person understand what the company policy was on you know, the length of time he could be off, what he must and must not do whilst he's off and you know, any insurance policies etc. you know around it, and all that information really helped them, you know calm themselves down a little bit, you know because obviously they were obviously very anxious about, you know, how it was going to be affecting them financially, you know, etc. And you know, we sort of like certainly were able to sort of get the information out you know, of him that, you know, he really wanted to return to work, you know even though from a financial point of view he probably wouldn't have been much, he wouldn't have been any worse off really because of the, you know the insurance policies etc. that X have got in place but he felt it was important to him to be able to do some degree of work for his own sanity, to prove to himself that he still had some capabilities not to, you know to accept defeat, you know that this illness, you know had beaten him. I think one of the things with him is that he has got a very addictive personality, yeah, so you know and I don't mean that, you know he takes drugs or anything (laughs)…

R (Laughs).

E I don't mean that but if he starts something he will become totally addicted to it and you know and this was just another thing that he was going to become addicted to

that he must make sure that he does not get beaten by it, yeah. So, all of that information that human resources were able to provide and etc. helped him so he really calmed down and not worry about certain aspects so that would help him rehabilitate in other ways, you know that the occupational health wanted him to concentrate on without having to worry about work aspects. Because obviously from, you know as I explained, his abilities were far in excess of anything we could ever expect to achieve, to get from any other person…

R Right.

E Be that someone that's you know that works with us now, nobody would be able to do what he does…

R Right, so he's got quite unique skills?

E He's very unique, very unique.

R Yeah. Can I, before I forget, and sorry to interrupt, can I just ask at what point did you start meeting, how long after the injury, can you remember was it weeks or months or…?

E It was probably about between two and three months I would have said.

R And was that instigated by yourselves or was it the person…?

E No, yeah, occupational health.

R OK, perfect, thank you, yeah.

E Yeah, yeah. The, right, from my point of view, you know I've said this was the first experience that I've had you know of this type of injury, so really you know knowing that X are you know they're quite unique as well and you know very human and understanding. So obviously from an HR point of view, from a company point of view, there's lots of things which covered him but from my perspective knowing how unique X is and knowing, understanding that you know the things that he was describing that he felt that he didn't, he felt as if he could remember everything from before but anything new he couldn't do. And also that you know he just didn't believe that he would you know, he just said, "I can't see me being able to do anything new but I can remember everything old." So what I had suggested and the occupational health were very happy to sort of go along with this, is that you know, obviously with him being off sick we you know, couldn't use him to do anything but me and my team we worked together to sort of fabricate some situations so that he (laughs) could do sort of like a paper exercise…

R Yeah, yeah, so dummy run type of thing?

E Yeah, and then feedback, you know I sort of assigned someone on the team who was X, you know almost, as I said there's nobody at the same level as him anyway but someone who's almost at that level so that we could feed him some pretend pieces of work and let him, you know write down, "Right OK, so this is the first thing I would do, then I would check such and such, then I would do such and such and I would then have a look at such and such," and you know just come up with a, you know tell us what he would do and then of course I, you know I got this other person to analyse you know what he would do so we could keep assessing if yes, he's remembered that, you know you're actually remembering far more than you think you can and assessing

how speedily he could do these things and you know and so on and so forth. So you know over the period of time that he was still off sick we did work with him to you know, to keep feeding him such things and then you know each of the meetings that we had we'd give feedback on how you know how he's getting on with those and made sure that he only spent you know, we said no more than, to start with it was an hour a week and then we upped it to, "OK, let's give you a couple of hours a week," and you know and so on and so forth just to, you know to sort of see what he could cope with.

R And how did that work?

E Yes, it was, I mean apart from the fact that he remembered a lot very well, we then moved into the realms of new things to see what he could, how he could use his brain for, you know, things that he'd never seen before, new functionality that's just been introduced that he would have known nothing about, you know last December when he had this episode. And yeah, you know, that brought about with it new things that you know again to start with he was looking at you know, he'd sort of say, "Right, well OK you know, it's taken me a long while but I've been able to X what it is and come up with some conclusions." But he could come up with you know, maybe a list of 20 decisions that he could make and it was that that he had the biggest problem with, that he said, "I can't," he said, "I can make a decision but the decision is purely based on, well I've got 20 options, I'll go for that one," he says, "I would not be able to tell you why I made that particular decision." So that was the next stage so, you know it was all about looking at, you know progressing at different stages and you know getting to the point where we'd helped him learn new ways of, you know of his brain connecting in different ways to be able to come up with reasoned decisions, yeah? And this is all still without touching anything you know, because obviously I made it clear to X, I said his name there, sorry (laughs)

R Don't worry, don't worry (laughs).

E Made it clear to him not to touch the X and he has, you know that is something that's my biggest problem with him, you know prior to this and everything he's so overzealous as well that you know sometimes you tell him not to do something but he thinks it's better that you do, so he does it, yeah and then that might cause a problem. So you know there's that that I you know I had to keep a very tight rein on, you must not access X at all, you are off sick and you know, apart from the fact that obviously when you're off sick it's not right that a company should be using you to do anything, it's also protecting the X because we don't know that you won't cause a problem.

R Yeah.

E Yeah. So and he understood all this, you know but I had to be firm with him as well, you know I wasn't pussyfooting or anything you know, I had to be totally, you know there with him and he's been absolutely fine with everything, he's not taken anything personally, I mean I haven't been offensive to him or anything…

E No, no, but it's reasonable.

E But you know making sure and you know that he knows you must not touch the X.

R So for what sort of period of time did you do these sort of mock ups?

E This was right up to when he was ready to be signed to come back to work because we effectively used that as the you know, the pillar to sort of say, you know, you are capable of doing something at some degree of work if you want to look at coming back.

R Right.

E Yeah, so we were sort of like you know, but if he felt that, and he'd been feeling that he was ready to come back but you know, and he has only come back but just in a part time capacity.

R Yeah.

E One of the other things that we started feeding to him as well is that the role that he was doing before, we, you know he was a singleton on that, you know so from a X point of view we hadn't covered our backs so it gave us a real big problem so I did have to find someone else to do that. Now, in the early days obviously when X wasn't, you know, he wasn't capable, they had to just muddle their way through that and try and unpick what he'd developed, you know and this is really quite a X and, but then part way through, say about three months after the, you know the initial rehabilitation work, we moved into, no not after, it was less than that, when we were happy that you know actually you're remembering a lot more, might be taking you longer as far as he's concerned, you know you're still doing it really quickly and you know you are getting the right answers, you're doing everything that you should be doing. So we started to, you know to help this other person out, and again with his permission and with the occupational health's permission, to allow this person who'd taken on this role from him, you know, having to sort of unpick everything that he'd built, you know over the years and understand it. There would be questions that this person had and of course he was the only one who was going to be able to answer these, so over the period of time when, you know there was a period of time when we just couldn't, you know I said to him, "No, you can't ask him, you can't," but we got to the point where we said, "Right, OK, if X's OK, and if the occupational health is OK then we'll allow you to be asked these questions, if you don't know the answer, just say it, it's fine, we've not lost anything, if you want to have a think and come back, again doesn't matter how long it takes you," you know. That's the other thing that I've made sure that even till now, now that he's returned to work, I've taken away any kind of pressure from him, yeah, so that he can concentrate on doing the bits that add value to me and don't worry him, yeah, so if there are deadlines, he might have a task to do but it's somebody else's job to worry about those deadlines, not his, yeah?

R Yeah

E So that worked really well, that helped him prove to himself that actually, this is all new stuff, you know this person's had to take it on, redevelop it effectively because of things that were already, you know it was something that he was going to have to do but then of course he went off, and you know and he was able to you know, reconfigure his brain effectively to be able to work on new things as well. So we knew by the time he was ready to return that he was ready to return because you know, he was already working as such, even though you know I sort of said to this person, you

know, “You’re the owner of this process now, not him, so whatever answers he gives to your questions, if you’re confident in that answer that’s fine, if you question it or you’re not happy with it, that’s also fine, it’s you know, it’s your decision whether you use his advice or not,” so that’s how we rode with it when he was off sick. And over all this time we never exceeded what we agreed between occupational health and X as to the amount of hours that he could do.

R Where did, I’m curious, where did this idea of these mock ups come from?

E Me.

R You?

E Yeah.

R What made you think that would help? I’m just interested.

E Well, I don’t know it was just, you know how sometimes you just think of something spur of the moment and yeah, I just thought, ‘Well I’m sure we can fabricate something,’ or even you know, something that’s already done, just give it him without giving him what the answers were…

R Yeah, so he can still go through the process.

E Yeah, so he can go through it. And do you know what there were some things that we’d done and closed off as being complete etc. and when we gave them to X to have a look at he came back, “Well, I’d do this, I’d do that and then don’t forget you would need to look at such and such,” and we were like “Oh my God, we never even thought about that” (laughs) you know, so you know, even so and of course you know I have kept feeding back him at various stages how valuable he is to me, you know how, even though he thinks that he is slower than he was before, he still does, you know the speed at which he does work and can work these things out is still sometimes a hundred times quicker than anybody else would be able to get there, you know and so all these things and he, you know and he does feedback, it obviously means a lot to him yeah. You know there must have been a big confidence knock, you know because of this and even now, even though from anybody else’s perspective you would look at him and think that he was absolutely fine but there this underlying, you know he has still got confidence problems, he needs reassurance regularly that he is doing OK, you know and I try and give that to him as well, so you know so there is that.

R So looking back on these sort of mock ups, what do you think were the benefits to him from your perspective? Did you see a difference in him by doing this?

E Yeah, because he, because initially he didn’t think he was capable, you know of doing anything or at least, you know, or he was, “I don’t know what I am capable of,” yeah, so yeah, but he already knew that he desperately wanted to end up somehow coming back to work in some capacity because he had to keep his brain active, won’t be defeated.

R Yeah, so there’s a way of all parties getting some sort of objective assessment of the situation.

E Yeah, that’s right, yeah, yeah. And it did, I mean it did help everyone come to the conclusion that he was capable of coming back to work in his current capacity so you

know, whereas if we hadn't have done any of this rehabilitation with him he may have had to come back to work at the lowest level for instance, or into an entirely different job but you know, which would have been a waste, so you know from my perspective I just needed to think of some way that I could prove that he either could do what he was doing before or he couldn't.

R Yeah, yeah.

E Yeah, so…

R And any of those other alternatives would have had an impact on everybody.

E Yes.

R Yeah.

E Oh yes.

R So what you were trying to do was get the right impact, the right situation in place before it actually happened.

E Yeah, indeed. And certainly the you know, I mean the end result is I've got X, I've got him back (laughs) you know. So you know if I hadn't have invested the, because it is time and effort, yeah, and you don't have the time but you know a) we've got someone who's feeling a lot better about themselves, I've still got a third, because he's come back to work and you know he's building his hours up, I don't think he'll ever go over like half time, you know about eighteen hours a week, I don't think he'll ever exceed that, but you know he's worked his way up from six hours to, he's going up to ten hours next week.

R So tell me how you did, tell me, so I've got as far as him being ready to return, tell me about his return, what you've done with his build up.

E Oh right, well one of the, just one of the final things that I suggested as part of his rehabilitation is that obviously when he was doing these mock ups he was doing them at home, so in a familiar environment with just his wife there, nice and quiet, no other distractions. So I suggested that one day he should come into the office, even though he was still off sick, come into the office and do his shift and practice from here and see how he coped with phones going, people talking around him, people maybe talking to him, yeah, and just see how he coped with that.

R Yeah.

E You know are we then liable for the fact that you know, he's had another episode because he's come in whilst, at our request, whilst he's off sick, you know, so, but in the end we, because we felt that it, and the occupational health agreed as well, that it was really quite an important aspect to determining whether he was ready to you know, to sort of come back to work, the occupational health were kind enough to say, "I'll tell you what, what we'll do is when he's coming in, you know just come in for an hour and we'll come in as well." So they came in and they sat with him for his shift, yeah, whilst you know, he worked and you know, and showed the, you know the distractions didn't, you know didn't cause him any distress, you know over and above, you know he was able to sort of filter that out whilst he was doing his other activity.

R And did you do that more than once?

E No, we just did it the once.

R The once, and it was just a case of just seeing that it was OK?

E Yeah, yeah.
R Can I just ask, again before I forget, was he driving himself at that point?
E Initially he was, yes, yeah, I think…
R So he was able to get himself here and everything…
E Yeah.
R Because that can be quite a big thing, can't it?
E Yeah, yeah. He, I think things have changed since in that, you know there's been other problems that he's sort of having which is, you know he's sort of like been tested for and in the meantime he's been told he can't drive.
R Right.
E But you know, he is an extremely fit person so he has, and he doesn't live very far away…
R So he can still get here.
E So he's really happy at walking in and walking home (laughs).
R Yeah, good, that's helpful, isn't it?
E Yeah, yeah.
R So he did this and then he returned six months from injury.
E Yeah.
R Clearly when he wanted to but was obviously initially scared that he couldn't do…
E Yeah.
R Help, you know, thankfully you sort of planned and plotted his way objectively, that he got that feedback and you did…
E Yeah.
R That he could actually come back…
E Yeah.
R So what was his return actually like when he physically came back?
E Yeah, it was good, yeah because you know, it was almost as if well, there's no difference now, yeah? Because again we had started to introduce him to real work by the questions and then, you know or as part of that then we allowed him to access, to look at things but not touch, yeah? So he could look at things and you know, to give greater you know, advice and yeah and it's you know, and he did stick to those, to the ground rules, you know which is very good because like I say he does have a tendency to not listen to what he's been told not to do, if he thinks it's better to do what he thinks then he'll do it and you know and damn the consequences later.
R Yeah, yeah.
E So you know, but yes his attitude seems to have changed, you know quite considerably as well because of this, you know, he's a lot more respectful of that and, you know and that there is a need to do what X ask for even though what they're asking for might not be what's best for them, you know so yeah he is better at that now as well.
R Right.
E The other thing that was, that needed you know, a close eye on is he can't leave work alone, yeah? (Laughs). So we were finding that he would be you know, logging on and looking at things, oh that was the other thing that I did, I made sure that he was

like removed from email distribution lists, knowing that he would be logging on and looking at things anyway, and you know and that other people in the X that, you know have a you know, a key involvement with him previously didn't include him on things…

R Yeah.

E So that, you know, and this was, like I say most of this was because it was important for me that, and it still is, that he does not get stressed.

R Yeah.

E Yeah, it's an extremely stressful job so the fact that he's now resource on the thing that he owned before…

R Yeah.

E Yeah, so he's doing what he did before…

R You've given the stress to somebody else.

E But the stress is with somebody else who's managing it…

R Yeah.

E Yeah.

R What made you do that? What made you just think that you should do that?

E Just common sense (laughs), you have to think of anything. I mean I think that is one of my strengths in that, you know I do you know, as a people manager and just as in a you know a people, I'm wouldn't say, I'm not a people watcher at all, but you know I do always try and think, you know even in a home life type situation, that if, probably if anything I go too far the other way and try and prevent them from having any kind of you know, any kind of you know stress and I take on too much myself…

R (Laughs).

E Yeah so I put myself under more stress than I ought to. But I think with him I was more, I could think more objectively around it, you know and sort of thinking that certain levels of anything are helpful to him, you know it's all rehabilitation so protecting him overly from something, it wasn't the right thing to do because one day he will be hit by stress of some sort so, you know just give him little bits but no more than what looks like…

R Not overwhelmed…

E You know, he's capable with and certainly nothing that he needs to have…

R No.

E So, what made me do it? Just that's how I am.

R Right, right.

E Yeah, so not the X, the X, what I have done is not what the X have told me to do…

R No.

E And we don't have that kind of policy in the X at all and if, you know if it had been someone right down at the bottom of the scale, yes I'm sure I would have done some, and now knowing how I worked through with this person, but if I'd not had this experience with someone who was so extremely valuable to me then, you know things may have been very different

R Yeah.

E Yeah, I may have treated it in an entirely different way, not put the effort into the part of helping them to return to some kind of work, I don't know because it didn't happen, so but I certainly know now, because I've had another experience from a personal point of view which is nothing to do with this but it would be useful for you to know. My X, she had a baby about X months ago, within weeks, you know, well straight after she got difficulties breathing, went to the doctors a number of times, just kept sending her home, got to a point a few weeks later that her mum who's a nurse said, "Come on, we're going to casualty." So they went to casualty and whilst she was in casualty her aorta burst, yeah, so otherwise she would have been dead if she hadn't been in casualty. But whilst she was in the operating theatre having that restored, she had a massive stroke, so she's been very, you know I've seen very similar things happen with her as I have with this guy, but the way that her company have handled her has been atrocious and this is X and, you know they've done nothing to help her rehabilitate at all, you know, over the period and, you know and it's got to the stage where in the last month they've called her in to you know, terminate her contract because she's, you know, she's not coming back. So you know, and her confidence is right down here, she's got nothing that's helped her in any way, she doesn't know what she's going to do in the future, you know so you know, I've seen it from both sides so, you know I've got that appreciation as well that you know, no matter how lowly a person's role is then there's something that we can always do to, you know to help so…

R Absolutely, absolutely.

E So that's the way I look at it now.

R Absolutely. Now this chap, how long has he been back now?

E Right, it must be X months, he was off for six months…

R So he's been back…

R Right, so he's back five and he came back sort of a couple of days a week or…?

E Yes.

R How did you work it?

E Well he came back for, initially it was six hours a week…

R Right.

E So that was three hours one day and then three hours a different, you know, a day's break and then the next day would be three hours and, you know and then over time that's increased to eight hours but the, from again continuing with the occupational health meetings, which they now come here…

R Yeah.

E And you know, we have that here, he was, you know he made it clear that when he goes home after his work shifts all he does is he sits in a chair and within seconds he's asleep, yeah it really, really knocks him out. He's absolutely fine when he's here, you know, really enjoys it, loves his job as, you know as I expected he would, he always has done, but he gets home after three hours work and he's had he's had it.

R Yeah.

E Yeah. Now, part, I sort of like, you know even though we've got to sort of you know a point where he, you know he was sort of saying, "The trouble is I feel I can do more hours, but I don't know how to get around this extreme tiredness."

R Yeah.

E So of course occupational health have been able to say to him, "That's totally normal, totally natural, don't feel as if, you know you're any different to anybody else, this is what's happening, etc." and you know and he was saying, the thing is, he says, "When I wasn't back at work and I, you know," he says, "I was doing, you know at least the same amount of time rehabilitation type work but I wasn't feeling the effects the same." So I said, "Well, is it perhaps that at home of course you can stop whenever you want, have a break, you know if you think, 'I've had enough for a minute,' you go away for an hour and then come back and do a little bit more?" You know I wasn't, I didn't say, you know you have to do it, well I did say I would prefer if you, so I can control how many hours he was doing, that he was sticking to them, that start at this time, finish at that time, drop me an instant message when you're starting, drop me an instant message when you're finishing and at least I'll know you're sticking to the times then. So we did that but we also knew that, you know we had some flexibility in that if you know he would drop me a note saying, "I'm going to knock off for a bit," and you know he could do it however he wanted, if he didn't want to do it one morning then, you know he said, "Oh do you mind if I do it tomorrow?" not a problem, you know, there was no commitment. If he didn't want to do it at all, OK yeah, don't have to do it today, that's not a problem, yeah, but obviously when you're back at work…

R It's different.

E You know you feel committed.

R Yeah.

E So you know I was saying, you know, "Is it perhaps a mixture of that having to come in the office, a) you've got to get here, so that's you know, extra time for you anyway but when you are here, because you're here such a little amount of time in comparison to your colleagues, you don't even feel as if you dare to get up and go and make yourself a cup of tea let alone go and sit downstairs for ten or fifteen minutes if you feel like you need a break," and he said, "Yes," so I said "Yeah," so that's that as well, plus that you know, a home you can spread your three hours out over the day if you want. Here, you've got to come in, and you go home so you've got three condensed hours, is that part of it as well, so yes actually it is. So you know so got to the nub of why that is and, you know although occupational health are saying, "You need to continue with this though because this is still part of your rehabilitation, you've got to learn to cope with that," yeah, "but don't feel that you know, how you're reacting when you get home is unusual or not how it should be."

R Yeah.

E But the fact that he was ready to put his hours up has suggested that rather than come in an extra you know, sort of like, come in one day, have a break, come in the next day, have a break and then come in the final day, what if the final day of the week you just do it from home.

R Yeah.

E Yeah, so you have two days when you come into the office, and then on the other day you just do it at home and he said, "Yeah, happy to do that." So that's what he's doing, that's the way that we're working at the moment.

R And how is that working out, is that going better, is he feeling that as an improvement, or…?

E Yeah, well it's, no it's working absolutely fine, yes it's no different to how it was because it's not, it would have been worse if he had been coming in an extra day…

R Yeah.

E Or increasing his hours on one of those days, you know where you've got a greater, you know condensed amount of hours at any one time, so he's just able to do more hours but he just works from home on that extra day.

R So five months in, he's working how many hours a week?

E He goes up next week to ten hours a week…

R Right, so and that's over three sessions, but two of them here and one of them at home?

E Yes, although I need to talk to him, that's only this week that he's been to the doctors again and got another certificate which effectively says he can increase it as per his feelings effectively.

R Yeah.

E So he's not given him a set amount but he did say that the doctor has been, you know putting the amount of hours that he could work a week on the certificate but what he is saying he thinks he can do, so the doctor is now changing that to your fit to work what you feel you can do as such, so we've said, "So you're happy to go to ten hours rather than eight?" "Yeah." So we need to talk about how we best do that from next week then.

R Week, right, so that's the next step really.

E Yeah, that's the next step.

R So it sounds like there's been more success factors than barriers…

E Oh totally.

R And if you don't mind me saying so, from my objective opinion that sounds like you've been a big part of that…

E Yeah.

R Because you've actually anticipated a lot of these difficulties, well you've prevented difficulties by being proactive…

E Yeah.

R And being very supportive of this individual.

E Yeah, yeah.

R Have there been any barriers at all that you can think of that have sort of made it harder?

E Yeah, do you know, no not at all. The way that we've worked through every single aspect of it has worked successfully and, you know and really that's, you know the thing that I was worried about was the amount of hours he's stuck to.

R Yeah.

E I did worry that if he was just doing things at home he would not be able to stop himself from looking and working on things and the other thing was, you know, I was worried he would X when I didn't want him to and, you know luckily neither of those things have been a problem

R Yeah.

E If they had been, obviously I would have had to do things differently and I may have had to withdraw the exercise…

R Yeah.

E Which might have had a completely different outcome…

R Yeah, yeah.

E Because you know, I have, after all's said and done my priority has to be that I protect the X…

R Yeah.

E And you know, but for me part of the X in this scenario was certainly making sure that if I could, if there was anything I could do to make sure it happened, that X is capable is coming back to work so…

R Yeah, yeah. Can I ask when he physically returned, how did, was there any sort of reaction in the team or the immediate office that he works in? How has that gone, has that gone OK?

E It's gone absolutely fine and again part of that is that I encouraged X to, oh (laughs)…

R Honestly, don't worry (laughs).

E We've been really trying hard…

R I'll just delete his name…

E Delete those bits, yeah. Encouraged him that when, you know when he got new certificates to come into the office himself and bring them, not post them, because that way he was introducing himself into the environment with his colleagues anyway so that all these, "How are you then?" and everything, "How's everything going?" and all that, he can get that done in bits and bobs, you know when he comes in, you know because to me being, in my mind if it was me and I'd been off for X period of time, my first day back at work, a) I've got to see if I can cope with being back at work and working and b) I've got the awful pounding fear of, I wish people would just say, "Morning," and then carry on, not say anything at all, you know. I mean I can't say to people, you know don't say, because he might not have wanted that, I don't know, you know but…

R But it was keeping in touch.

E Yes, keep in touch and you know, little bits and you know, and then at least you've made that sort of contact and then on the day that you come in, you know but a part of him coming in that time on his rehabilitation was to see how he coped with the, you know knowing he wasn't really going to be doing anything, you know come in and see how he coped with, you know people interaction, you know and yeah, he was fine so day one went without a hitch. I made sure that on day one myself and his team leader, because you know, I'd kept, you know his team leader abreast of the situation and what I needed him to be, you know keeping a very close supervisory eye on, you know what he was doing on his return and then giving him feedback, you know at the

end you know the week to say a) how did he feel it had gone, how did we feel it had gone and so on and so forth. The, so yeah, it went really well, yeah, really well.

R Good.

E So the only I say negative thing to come out of it was that, you know he obviously felt that, you know realised that right, comes back to work, means I go home and I'm zonked…

R Yeah.

E Which just hasn't really gone away, yeah.

R No, no.

E I did also make sure that all the, you know the people who don't work in this particular office, you know all his immediate colleagues, that even though he has returned, and you know, sort of put something out to all the people that would use him, so if they all of a sudden saw emails from him or saw him on distribution lists etc. that he'd returned and, you know I thought, 'Better that I actually announce that he is returning,' but I also set some ground rules as well saying, "Right, we managed without him for six months, we can manage without him now. If you have any questions or issues you approach me, his line manager…"

R So again sort of protecting him…

E Protected him from the, yeah, I wasn't protecting him i.e. that we wouldn't use him to answer any of these questions…

R No, but the volume…

E But I didn't want him to be, you know I needed to make sure that people knew he was only returning part time, that he will be working on things that I've given him and I don't want other people bombarding him with other questions or asks, etc., any requests for him to do anything have to go through his line manager and his line manager then makes a call on whether he asks him or, you know or someone else, but again he is protected from, you know from any deadlines that other people might be…

R Working to…

E [inaudible] (laughs).

E Exactly, that's good (laughs).

E Yeah.

R Now, just to round up, how does it feel as his line manager, having him back?

E Great, really, yeah.

R So what's the greatest bit about having him back?

E The fact that the things, a) his brain has effectively, he's obviously using his brain in an entirely different way, yeah, but his capabilities have not waned, well they obviously did to start with but he's been able to build up to the point where, you know, he's able to make different kind of connections and do just as complex work as he did before.

R Yeah.

E And the amount of value that he has provided to us since his return and especially in these last two months, if it hadn't have been for him I don't think we'd have been anywhere near as good as we are now

R Brilliant. How do you think he feels being back? Well you probably know how does he…?

E Yeah, he's yeah, he's proud of himself and as I say, he is, and both myself and his line manager have sort of like independently, you know told him how much we value him and how important it is to us that he's cared for and, you know that if he has issues, you know he comes to us, we'll work with him in any way that's necessary because it's so important that you know, even the tiniest amount of time he can give us is more valuable than, you know than anything…

R Brilliant.

E And yeah and he is, you know sort of so appreciative and says, "You actually really don't know how…" what words did he use? "Well, just how much that means to me to hear that," you know, so yeah.

R Lovely. Anything else you want to add before I turn the tape off?

E No, I don't think so. I mean you know, now that he's back, you know we're not stopping at that, you know this will just continue, you know going forward, you know he's never going to be in a position where he can withstand the kind of pressures that he had before…

R Yeah.

E And you know, and it's important to me that I protect him from, you know having those kinds of pressures so I will never let that drop, yeah.

R Yeah, yeah.

E Yeah.

R Good. Shall I turn it off?

E Yeah.

R Thank you very much.

Appendix 16 Final Phase one themes at 24/8/11

The themes were established from collapsing and clustering the meaning units into themes/constituents/phenomenon that described the psychological insight within them;

6 phenomenon/themes over 61 meaning units were established. All analysis decisions are recorded at the end of this document.

6 Themes	**Relevant meaning unit**
1. Theme 1; Coping with ongoing difficulties	**1.** Ongoing residual cognitive issues (**Part 1, 3 x 2, 4 x 2, 5 x 2, 6 x 4, 9, 10 x 5, 12 x 6, 13 x 2, 14, 16 x 3)** **2.** Impact of fatigue (**Part 1 X 2, 2, 3 x 3, 4 x 2, 5, 7 x 2, 8 x 3, 9 x 4, 10 x 2, 12 x 2, 13 x 3)** **3.** Transport issues (**Part 5 ,6 x 3,8, 9 x 3,10 x 3, 11 x 2,12, 14)** **4.** Barriers to self-worth (**Part 6,8,9, 11** **5.** Discrimination (**Part 2) &** Labelled disabled (**Part 1**)=Discrimination **6.** Frustrations (**Part 1, 14)** **7.** Lack of information (**Part 4,9,10 x 2,15)** **8.** New learning (**Part 1,4,10)** **9.** Residual physical problems (**Part 1,2 x 2,8,15 x 2)** **10.** Residual mental health problems (**Part 2,9 x 2, 11,12) &** Post traumatic stress (**Part 8) &** Anger (**Part 3,13) named** Residual mental health problems **11.** Residual social problems (**Part 9) &** Relationship issues (**Part 4) & renamed** social problems **12.** Abusing opportunity (**Part 7 x 2**

	13. Early post BI needs (**Part 9 x 2)** **14.** Busy environment (**Part 9,10, 11) &** Noise pressure (**Part 1,3,13) renamed** environment issues 15. Setbacks (**Part 9) &** Dealing with setbacks (**Part 9) named** set backs **16.** The benefit system (made up of Benefit issues (**Part 2 x 7,5, 6,7,9 x 3,10, 12 x 3, 15 x 2) &** Coming off benefits (**Part 2,9,12) &** RTW benefit options (**Part 2)=renamed** benefits **16 MUs confirmed at 24/8/11**
2. Theme 2; Expectation and timing of return to work	**1.** Expectation to rtw (**Part 1 x 4, 2 x 2, 3 x 2, 5, 6 x 4, 7 x 3, 8, 12, 13 x 2, 14 x 2, 15, 16 x 2)** **2.** Fast return to work (**Part 2 x 6,4 x 4, 9 x 2, 10 x 2, 15)** **3.** Slow phased return (**Part 1 x 3,5 x 2,6 x 2,7 x 4,8, 9,16)** **4.** Sick note period (**Part 2)** **5.** Working speed (**Part 6)** **6.** Reaction to slow phased return (**Part 7)** **6 MUs confirmed at 24/8/11**
3. Theme 3; Workplace colleague reactions	**1.** Colleague reactions at work (**Part 1 X 7,2 x 3,3 x 2, 6 x 3, 8 x 4, 11 x 3, 13 x 2)** **2.** Line manager issues (**Part 2 x 2,4 x 4,8,10 x 2,14 x 6, 15)** **3.** Lack of sympathy (**Part 1 x 3)** **4.** Bullying (**Part 14 x 2)** **5.** Feeling unwanted (**Part 14)** **5 MUs confirmed at 24/8/11**

4. Theme 4; Things that help	**1.** Professionals who helped (**Part 2 x 3,4 x 2,5, 6,9 x 4,10,11 x 4, 12)** **2.** Helpful colleagues (**Part 4,5 x 4 ,7 x 2,12,16 x 3)** **3.** Helpful managers (**Part 3 x 2,4 x 4, 5, 6, 7,13 x 2)** **4.** Access to work (AtWS) (**Part 1 x 2, 8 x 4, 12)** **5.** Family support (**Part 1 x 2, 3,13)** **6.** Financial support (**Part 1)** **7.** Positive practical support (**Part 1 X 2,2 x 2, 4)** **8.** Positive mental strategy (**Part 1)** **9.** Positive work pre supportive messages (**Part 1) &** Positive pre links with work (**Part 1)- renamed** Positive pre links with work **10.** Helpful environment (**Part 9)** **10 MUs confirmed at 24/8/11**
5. Theme 5; Change and return to work options	**1.** Job restructuring (**Part 1 x 2, 2, 5 , 6 x 2, 8 x 3, 9, 14 x 3)** **2.** Alternatives options to rtw (**Part 2 x 11)** **3.** RTW factors (**Part 1 x 5,2 x 2,5,14, 15)** **4.** Workplace had moved on (**Part 1,6 x 4,7, 14 x 3,16)** **5.** Loss of job post rtw (**Part 1,2 x 3,16 x 3)** **6.** Job coaching (**Part 9 x 7)** **7.** Adapting to change (**Part 4 x 3, 7 x 2, 15) &** Difficulty coping (**Part 3, 13)** **8.** Jobs found themselves (**Part 4 x 2)** **9.** Medical retirement (**Part 1,11) &** Medical discharge (**Part 4)=**Medical retirement **10.** Practical rtw issues (**Part 1, 6)** **11.** Reactions to alternatives to rtw (**Part 2)** **12.** Work retraining (**Part 2 x 3,4 x 3) &** Result of work retraining (**Part 2 x 2)** **13.** Workstep (**Part 4)** **14.** Workbridge (**Part 9 x 3)**

	15. Work placements (**Part 9 x 4,11,12)** **16.** Mentor to others (**Part 9)** **17.** Work solutions (**Part 12)** **18.** Shaw trust (**Part 12, 15)** **19.** Voluntary work (**Part 3 x 2,13 x 2)** **19 MUs confirmed at 24/8/11**
6. Theme 6; Feelings of success	**1.** Feeling of success/achievement (**Part 1 x 2,3,9 x 2,13,15,16 x 3)** **2.** Feeling whole again (**Part 1 x 4,2, 12)** **3.** Insight/self-awareness (**Part 3,4,13, 16 x 3)** **4.** Personal perceived change (**Part 1)** **5.** Returning to health and work (**Part 1, 9)** **5 MUs confirmed at 24/8/11**

All themes were renamed to describe psychological insights within them;

- Theme 1 renamed Coping with ongoing difficulties
- Theme 2 renamed Expectation and timing of RTW
- Theme 3 renamed Workplace colleague reactions
- Theme 4 renamed Things that help
- Theme 5 Change and return to work options
- Theme 6 Feelings of success

Therefore final phase 1 data findings;

6 themes over 61 meaning units;

- Theme 1 Coping with ongoing difficulties (16 MUs)
- Theme 2 Expectation and timing of RTW (6 MUs)
- Theme 3 Workplace colleague reactions (5 MUs)
- Theme 4 Things that help (10 MUs)
- Theme 5 Change and return to work options (19 MUs)
- Theme 6 Feelings of success (5 MUs)

Summary of final 6 themes and 61 meaning units within them

Theme 1; Coping with ongoing difficulties

- Ongoing residual cognitive issues
- Impact of fatigue
- Transport issues
- Barriers to self-worth
- Discrimination
- Frustrations
- Lack of information
- New learning

- Residual physical problems
- Residual mental health problems
- Residual social problems
- Abusing opportunity
- Early post BI needs
- Environment issues
- Set backs
- Benefit issues

Theme 2; Expectation and timing of return to work

- Expectation to return to work
- Fast return to work
- Slow phased return
- Sick note period
- Working speed
- Reaction to slow phased return

Theme 3; Workplace colleague reactions

- Colleague reactions at work
- Line manager issues
- Lack of sympathy
- Bullying
- Feeling unwanted

Theme 4; Things that help

- Professionals who helped
- Helpful colleagues
- Helpful managers
- Access to work
- Family support
- Financial support
- Positive practical support
- Positive mental strategy
- Positive pre links with work
- Helpful environment

Theme 5; Change and return to work options

- Job restructuring
- Alternatives options to return to work
- Return to work factors
- Workplace had moved on
- Loss of job post return to work
- Job coaching
- Adapting to change
- Jobs found themselves
- Medical retirement
- Practical return to work issues
- Reactions to alternatives to return to work

- Work retraining
- Workstep
- Workbridge
- Work placements
- Mentor to others
- Work solutions
- Shaw trust
- Voluntary work

Theme 6; Feelings of success

- Feeling of success/achievement
- Feeling whole again
- Insight/self-awareness
- Personal perceived change
- Returning to health and work

Appendix 17 Final Phase two themes at 15/3/13

Summary of meaning units from 11 employer transcripts

Meaning unit	Employer transcript
1. Early injury fears	Employer 1 X 2 Employer 4 Employer 11 x 3
2. Early contact	Employer 1 Employer 2 Employer 4 Employer 7 x 3 Employer 8 x 2 Employer 9 x 2
3. Early injury adjustment	Employer 1 x 4 Employer 2 x 3 Employer 4 x 3 Employer 5 x 2 Employer 6 x 2 Employer 8 x 4 Employer 11 x 3
4. Early support	Employer 1 Employer 4 x 3 Employer 8 Employer 9 x 4
5. Early rehabilitation	Employer 1 x 2 Employer 4 x 3 Employer 8 x 2 Employer 9 x 2 Employer 11
6. Fatigue	Employer 1 x 3 Employer 3 Employer 4 x 2 Employer 6 Employer 8
7. Employer support	Employer 1 Employer 2 Employer 3 Employer 5 x 3 Employer 6 x 2 Employer 8 x 5 Employer 9 x 8
8. Workplace knowledge of brain injury	Employer 1 Employer 2 Employer 6 x 3 Employer 7 x 5
9. Drive to return	Employer 1

	Employer 4 Employer 8 Employer 11 x 3
10. Planning to return	Employer 1 x 2 Employer 5 Employer 9 x 3
11. Tensions	Employer 1 Employer 2 Employer 9 Employer 10
12. Time taken to return to full time	Employer 1 Employer 2 Employer 11
13. Driving	Employer 1
14. Helpful factors	Employer 1 Employer 2 Employer 3 Employer 5 Employer 9 x 4
15. Feeling in control & Sense of control= Feeling in control	Employer 1 x 2 Employer 11
16. Barriers to return	Employer 1 Employer 5 Employer 6 Employer 9 x 3 Employer 10 x 6 Employer 11 x 3
17. Employers thoughts	Employer 1 Employer 2 x 2 Employer 3 Employer 5 x 2 Employer 10 x 2
18. Employer insight	Employer 1 Employer 3 Employer 5 Employer 6 Employer 7 Employer 9 x 2
19. Work ethic	Employer 2
20. Positive colleague attributes	Employer 2 Employer 4 Employer 6
21. Acceptance of disability	Employer 2 Employer 6
22. Pre return to paid work	Employer 3 x 2 Employer 10 x 4
23. BI outcome of return	Employer 3 x 3

	Employer 4 Employer 5
24. Accepting a changed job role	Employer 4 Employer 6 x 2
25. Disclosure of disability	Employer 5
26. Training to return	Employer 5
27. Advantages of employing a BI person	Employer 5 Employer 8 Employer 10
28. BI permanent disabilities	Employer 5 x 5 Employer 10 x 2
29. Employers understanding benefits & Benefits issues= Benefit issues	Employer 2 Employer 3 x 2 Employer 5 x 2 Employer 10 x 3
30. Patient confidentiality	Employer 6 x 2
31. Occupational health	Employer 6
32. Competence proceedings	Employer 6 x 5
33. Lack of insight	Employer 6 x 4 Employer 7 x 2
34. Disability discrimination act	Employer 6
35. Support provided to help employer	Employer 6 x 2
36. Pressure on employer	Employer 6
37. Long term colleague reactions	Employer 6
38. Redundancy consultation	Employer 7 x 2
39. Helpful advice to employer	Employer 7
40. Long term sickness policy	Employer 7
41. Information from GP	Employer 7 x 4
42. Fit note	Employer 7 x 2
43. Long term capability	Employer 7
44. Ill health terminations	Employer 7 x 3
45. Phased return	Employer 9 x 2 Employer 10 x 2
46. Best method of employee communication	Employer 9
47. Colleague support	Employer 9
48. Employer unable to talk about BI	Employer 10 x 2
49. Colleague reactions & Reactions to colleagues= Colleague reactions	Employer 10 x 2 Employer 2 Employer 8
50. Disciplinary process	Employer 10

Employer 6 themes established from the 50 meaning units

Please note that the order of the following themes has been rearranged to improve reader presentation in chapter 5.

Theme	Meaning Unit
1. Supporting employees to cope with loss and adjustment	1. Early injury fears 3. Early injury adjustment 9. Drive to return 15. Feeling in control 19. Work ethic 21. Acceptance of disability 24. Accepting a changed job role 7 Meaning Units (MUs)
2. Providing practical and emotional support to employees	4. Early support 7. Employer support 35. Support provided to help employer 3 MUs
3. Learnt insight	14. Helpful factors 17. Employers thoughts 18. Employer insight 20. Positive colleague attributes 23. BI outcome of return 27. Advantages of employing a BI person 31. Occupational health 39. Helpful advice to employer 46. Best method of employee communication 47. Colleague support 10 MUs
4. Providing rehabilitation	2. Early contact 5. Early rehabilitation 10. Planning to return 12. Time taken to return to full time 22. Pre return to paid work 26. Training to return 34. Disability discrimination act 40. Long term sickness policy 45. Phased return 9 MUs
5. Awareness of on-going employee difficulties	6. Fatigue 13. Driving 16. Barriers to return

	28. BI permanent disabilities 33. Lack of insight 5 MUs
6. Facing challenges	8. Workplace knowledge of brain injury 11. Tensions 25. Disclosure of disability 29. Benefit issues 30. Patient confidentiality 32. Competence proceedings 36. Pressure on employer 37. Long term colleague reactions 38. Redundancy consultation 41. Information from GP 42. Fit note 43. Long term capability 44. Ill health terminations 48. Employer unable to talk about BI 49. Colleague reactions 50. Disciplinary process 16 MUs

Appendix 18 Idiographic portrait: Participant one individual following a brain injury.

Background

Melvin is a 51-year-old man who had a subarachnoid haemorrhage and acquired brain injury when he was 39 years old. His job at the time of his injury was Sales Manager for a Global Banking Company. The following idiographic portrait describes his lived experience in relation to the six themes that emerged following phase one descriptive data analysis. They are not in thematic order but in the sequence of his lived experience.

- **Theme 1 coping with ongoing difficulties**
- **Theme 2 expectation and timing of return to work (RTW)**
- **Theme 3 workplace colleague reactions**
- **Theme 4 things that help**
- **Theme 5 change and return to work options**
- **Theme 6 feelings of success**

Things that help

Melvin remembered that from the day he had his haemorrhage that his line manager was a good link back to his workplace, although at this time he was more worried about getting back to good health. He remembered when he woke up post injury realising that if he needed he could have a year off work and that his employer was going to be supportive, as he had had positive messages and felt that encouraging.

Three months before returning to work (nine months post brain injury) occupational health were involved and offered him encouragement and helpful tips. They suggested he should start meeting colleagues before going back in order to get back into seeing them and them seeing him.

Workplace colleague reactions

As return to work approached occupational health advised that colleague reactions may not be encouraging and that some people may not know what to say and rather than say the wrong thing they may not say anything, and that this may feel like they were totally ignoring him and “that is exactly what happened”. Some people walked away when

Melvin approached leaving him feeling incredibly hurt but others were welcoming and made him feel better.

Change and return to work options

A big, immediate problem was that “a lot of the people had changed as it was a year since leaving work “and some had moved on, new people had come in so Melvin felt like a “new boy again”.

Melvin had to “relearn the job “ as he had been out for so long and had forgotten aspects of it and “didn’t really know when he returned what his future role was going to be”, because even he could see that it was going to take a long time to get back. His line manager was helpful, and agreed that Melvin could work half a day each fortnight.

Coping with ongoing difficulties

He suffered greatly from fatigue and felt exhausted just going into work on the train, “it sounds pathetic but it was just such a huge load being put back on my brain, you know my brain was working ten times as hard as it had been for the previous year”.

Things that help

The Access to Work Scheme completed a workplace assessment and Melvin was provided with voice recognition software and a vertical camera to compensate for his residual visual difficulties. His employer also provided a laptop and the prescribed visual equipment to allow him to also be able to work at home. This made Melvin feel that he was going to get back into work quicker and that a huge commitment had been made to help him.

Expectation and timing of RTW

He returned to work very gradually, four hours (a half day) each fortnight, then two half days each fortnight, then three, four and five. Then his working day was lengthened.

Coping with ongoing difficulties

His fatigue continued to worsen the more he did. It was approximately 18 months before he worked full time. The ongoing problems of fatigue, reduced vision, speech and short-term memory difficulties required ongoing treatment.

Transport by train (an hour and 20 minute one-way journey) was problematic, “I just couldn’t stand so many people”. He had to avoid busy times but once he had to travel during busier times he found it unnerving and it took him months to get accustomed to it again. Melvin believed it was because he had spent so much time with fewer people and was never on his own from the day he had the haemorrhage. Also he thought it was because he felt that he “deserved more sympathy and of course they (the public) didn’t care cause they don’t know”.

Expectation and timing of RTW

Melvin never doubted that he would return to work although medical retirement was discussed. He made it clear to everyone that he would return to work. He was 39 and did not want to retire. He is now retired aged 51 but sustained return to work for 12 years.

Workplace colleague reactions

Practical difficulties were quickly sorted out but people’s attitudes towards him hurt, “people actually saw me coming and they would pick the phone up so I couldn’t talk to them and I could see them doing it, I felt really hurt”. Some senior managers made him feel difficult at times because they had assumed that he “was incapable of doing anything”. Occupational health needed to speak to one of his managers but the biggest thing for Melvin was every time he had a health set back (4 residual operations) he had to start all over again each time and by age 51 he believed that he just “couldn’t do it anymore”.

Expectation and timing of RTW

Sustaining work for him was down to his determination to get back to what he “was before” and that his primary goal was to get back to what he had done before. Returning to work helped as it was for him getting back to his “sense of the familiar which was comforting because so much had changed”. He craved something that had stayed the same so getting back to work was what he wanted and something he really enjoyed. He

set himself back to work goals “I said to myself once I can do that I ‘m back, I’m back to work and where I was”.

Feelings of success

On achieving these personal set goals there was a huge sense of achievement; “the sense of relief when I achieved that as well as of elation of achieving that goal”. He worked hard but it was something he had to do so it was s relief when he did it and he wanted to congratulate himself, “it felt like I was almost made whole again and that had taken a long time afterwards, took me two and a half years to get back full time so it may have been another couple of years after that so maybe five years to travel again and it was a massive journey perhaps 10 times that length”. His relief was great.

Expectation and timing of RTW

Melvin felt on some days that he had made the wrong decision. However he was driven to go back to work and to do it and be successful because he looked at his job as a big part of who he was. He wanted the recognition for having his job and the level of seniority was important to him.

Change and return to work options

He believes that he would have failed had he not returned to his old job and that “it would be more stressful going into a job where I had to learn from scratch to a team and people I didn’t know”. He needed a sense of the familiar and that is what he wanted and found comforting because he had experienced a crisis of confidence because of what had happened to him.

Appendix 19 Idiographic portrait: Employer participant one.

Background
Pheobe is a 49-year-old middle manager in a large public sector organisation. She is the direct employer of Linda who is a 50-year-old administrator who suffered a brain haemorrhage and returned to paid work following four and a half months sick leave. The background to Linda's brain injury (as told by her employer, Pheobe) was that Linda called to say that she was experiencing vomiting and double vision. Linda presented at Accident & Emergency and was sent home. A couple of days later her situation deteriorated and she attended her General Practitioner who referred her immediately to a specialist regional hospital. Once she got there it was confirmed that she had had a brain haemorrhage.

The following idiographic portrait describes Pheobe's lived experience in relation to the six themes that emerged following phase two descriptive data analysis. They are not in thematic order but in the sequence of Pheobe's lived experience.

- **Theme 1 Supporting employees to cope with loss and adjustment**
- **Theme 2 Providing practical and emotional support to employees**
- **Theme 3 Facing challenges**
- **Theme 4 Learnt insight**
- **Theme 5 Providing rehabilitation**
- **Theme 6 Awareness of ongoing employee difficulties**

Supporting employees to cope with loss and adjustment
Pheobe observed and also felt great fear and anxiety at the poor management of Linda's early diagnosis and felt let down by the NHS.

Providing rehabilitation
Communication with Linda was daily and often by text when Linda felt well enough to communicate.

Supporting employees to cope with loss and adjustment
Pheobe was aware that Linda felt extremely anxious about returning home and scared regards what was going to happen and how her brain injury would affect her life. She observed Linda being quite demoralised and losing her sense of identity. Pheobe realised that Linda's personal perception of herself left her feeling completely displaced and devalued even though her friends and relatives did not convey this. Linda explained to Pheobe that she didn't know who she was any more and that was the overriding thing that made Pheobe feel upset to think that Linda may never get over that loss.

Providing practical and emotional support to employees
Linda resisted Pheobe or any colleagues visiting her so no one saw her for about two and a half months post discharge so a lot of remote support was provided from Pheobe and colleagues.

Supporting employees to cope with loss and adjustment
Pheobe felt close to Linda pre injury and found the refusal to allow her to visit Linda difficult until Linda told her that she felt a real feeling of shame and embarrassment and fear that Pheobe wouldn't recognise her.

Providing rehabilitation
Pheobe remembered that Linda's first trips out were just to the end of the road with family and that it took a long time before a trip out in a vehicle and several months before Linda used public transport.

Awareness of ongoing employee difficulties
Pheobe observed that Linda felt absolutely exhausted doing even the smallest things and that this varied from day to day.

Providing practical and emotional support to employees
Pheobe had some contact with Human Resources (HR) and felt that this was positive as Linda had all sorts of anxieties. Pheobe felt that support; encouragement and a very gentle approach in parallel with advice from Linda's Consultant were all helpful.

Facing challenges
Linda reported to Pheobe being pleased that the HR person had a lot of experience in dealing with people who had brain injuries and felt a great sense of empathy and understanding and reported that her journey could be very different from any other HR person without this experience.

Supporting employees to cope with loss and adjustment
Pheobe observed Linda starting to feel a sense of control over her return to work. The plan was a phased return where Linda was contacted at every stage and understood that it was a two way process and that she could slow it down if she wanted. Linda confided in Pheobe that she felt ashamed of how she looked visually, that she didn't smile anymore and that she had no sense of humour anymore and that she couldn't see it changing.

Providing rehabilitation
Rehabilitation steps forward were tiny. At a later date Pheobe found out that Linda would plan the steps she wanted to achieve each day and wouldn't tell anyone as she found it easier to manage the disappointment alone rather than sharing it.

Supporting employees to cope with loss and adjustment
Linda started to change the moment she went outside, as she had to put on a different appearance where inside she could feel sorry for herself, disappointed and sad. Going outside was not just physical as it made her feel better. When she had contact with people and positive feedback she started to feel good about herself.

Providing rehabilitation
A collaborative plan was drawn up to work three-hour blocks. Then she gradually built this up and devised her own timetable in conjunction with HR and the occupational health support person. This plan was then relayed to Pheobe and Linda's colleagues.

Awareness of ongoing employee difficulties
Linda tired really quickly. She would lose the strength to lift things and reported that she would often start a sentence and not finish it and perceived that her voice was slurred. Pheobe only saw fractional changes in Linda's speech.

Facing challenges
Pheobe had to manage a little staff conflict where staff covering some of Linda's duties did things differently to the way Linda did. As Linda's confidence grew there were a few instances of tension where she wanted her previous role back.

Providing rehabilitation
It took Linda five months from her return to get back to full time working.

Providing practical and emotional support to employees
Pheobe reported that having no pressure, as much time as Linda needed and allowing her to recover at her pace all helped her return to work.

Supporting employees to cope with loss and adjustment
Pheobe thought that Linda coped best when she felt in control and that she could change the return to work plan. Also having her job role completely covered when she wasn't there helped her to cope.

Awareness of ongoing employee difficulties
Barriers to return to work were about Linda's self-doubt, and Pheobe and colleagues seeing that Linda's personality had changed.

Learnt insight
Pheobe never thought that Linda would make it back to working full time but respected her courage. There seemed to be more risks for Linda trying and potential failure so Pheobe felt a real sense of achievement to see Linda get back to work.

Appendix 20 Phase one descriptive summary

A general situated structure of return to paid work following a brain injury

The intention of this study was to explore the phenomenon return to paid work as expressed by 16 individuals following a brain injury. A general description of this structure is presented below and has been devised following careful reflection of all of the participant's lived experience narratives. It does more than summarise one injured participants experience and provides a comparison of each individual's idiographic portrait following a brain injury. The summary has been prepared to identify the range of the individuals lived experiences and the perceptions of the researcher, whilst forming the general structure return to paid work following a brain injury. Wertz's (1985) study provided a useful template for presenting the structure in an organised and coherent way. The summary is presented using the six emerging themes following thematic analysis of the 61 meaning units established from participant's interview transcripts. The six themes presented below are; coping with ongoing difficulties, expectation and timing of return to work, workplace colleague reactions, things that help, change and return to work options and feelings of success.

Coping with ongoing difficulties

Participants identified coping with ongoing difficulties as a factor influencing their return to paid work. Ongoing cognitive difficulties, mainly poor memory and slow information processing meant participants had to attend therapy whilst returning to work, use memory aids which at worst resulted in mistakes being made and being the cause of arguments in the work situation in addition to their speed of learning new material being affected. Ongoing fatigue manifested in different ways and tiredness was explained as different from before injury and being caused by the simplest of tasks. Preparation of participants to deal with ongoing fatigue had been poor and for some the consequences of it was having to sleep secretly for short periods at work, making mistakes, being absent from work and losing their job. Transport was an issue for participants unable to drive due to having had an epileptic seizure post injury and being unable to get their driving licence back from the DVLA. This was a barrier to all jobs involving travel resulting in participants relying on taxis, buses, voluntary drivers, family and where possible walking and cycling to work. All participants experienced setbacks and stressed the importance of being able to take the time to pick them up and to try again as in their experiences set backs were inevitable. Ongoing benefit issues affected most and benefits received varied and followed no set pattern causing anxiety at a time when participants were vulnerable and trying to recover. Coming off benefits was complex with no participant coached through the best way neither to return to paid work nor to deal with coming off. Some participants experienced mental health problems and suffered from; depression, agoraphobia, paranoid feelings, post-traumatic stress and anger. Participants described

experiencing anxiety in crowded places where there were lots of people and in enclosed environments felt claustrophobic. Tolerance to noise was also identified as an ongoing difficulty as well as lack of information in relation to how to best return to work.

Expectation and timing of return to work

Participants expressed their expectation and timing of return to work' as a factor in their return. Most participants described a determination and drive to return to work that came from them and not others. This appeared to be related to pushing themselves back to work in order to be able to see them as they were before their brain injury and their previous occupational identity. They wanted to get back to pre-injury normality. A slow phased return to work was experienced by most participants and the majority had a positive return to work. This ranged from six to 18 months before working full time post injury. Most participants returned very part time hours initially ranging from a half day per fortnight and gradually building this up to working two to three days with break days in between. The slow planned return appeared to be not only more successful but also more satisfying for participants. In comparison a fast return to work was experienced by some participants ranging between four to eight weeks post injury. This resulted in a poor experience of return and in failure particularly for self-employed participants. The consequences of a fast return included participants becoming suddenly very aware of memory problems, attention deficits, fatigue, pain, being demoted, and facing failure and in a loss of their job.

Workplace colleague reactions

Participants expressed workplace colleague reactions as a factor in their return. Participants described colleague reactions towards them as being hurtful and negative. Some participants perceived that if something went wrong that they would be blamed. They reported being left alone a lot, feeling unsure how supportive colleagues really were, being treated like a child and being socially excluded. It appears that colleagues with no knowledge of brain injury were the most problematic and although understandable this proved difficult. Colleagues were described as having little tolerance and as forgetting that participants had ongoing difficulties to deal with. It appears that due to the fact that some brain injury difficulties weren't visible it was hard for colleagues to understand them and to accept that they were real. Some participants also experienced line manager issues where they had negative experiences with managers. Some described that they felt like they had to go back to work and perform and to work twice as hard as their colleagues. Line manager issues experienced were being given demeaning tasks and not real work tasks, an unsympathetic approach and lack of understanding of participant's problems. The above resulted in participants feeling unwanted and perceiving a lack of sympathy in the workplace.

Things that help

Participants expressed 'things that help' as factors in their return to work. Identified were professionals who helped and were reported as; social work, D4 (a local council support service), hospital case management, the disability employment advisory service (DEA), brain injury rehabilitation teams, occupational therapists, occupational psychologists, Rehabilitation UK (a national support service), Workbridge (local sheltered employment) and Headway (a national support charity). Professional help included social work advising on benefits, D4 (an agency that helps disabled people) help with CV preparation and help with confidence to sit in interviews if needed. The brain injury rehabilitation team liaised with employers and occupational therapy working within headway with return to work advice and with sessions to help use public transport and to learn new routes. The DEA was helpful in putting participants in touch with Workbridige and Rehabilitation UK teaching how to use computers, decide which jobs to apply for and with support to get a job.

Helpful colleague attributes experienced were tolerance, flexibility and a relaxed attitude and were seen as key to facilitating return to work. Especially when some colleagues were prepared to put themselves out to help participants and where colleagues made participants feel like they were needed. The biggest help experienced was where colleagues understood the ongoing brain injury difficulties participants faced. Helpful manager attributes experienced were where managers were supportive, who thought carefully about the staff that participants were placed with, understanding, those who helped if participants made a mistake and those with an easy-going attitude.

A few participants were helped by the Access to Work scheme where they had a work place assessment which either resulted in referral to another organisation that would help (i.e. Royal National Institute for the Blind), for the purchase of specialised equipment (i.e. voice recognition software) or where they were awarded access to work transport to and from work (i.e. a taxi paid for to take to and from work every day). As well as practical this was financial support that helped.

Change and return to work options

'Change and return to work options' was expressed by participants as a factor in their return to work. Following return to work job restructuring was experienced by half of the participants. This included having to reapply for their own job and being unsuccessful to being made redundant. Participants lived in anxiety when restructuring was happening, as they perceived it would be them that went first and not others. Several participants stressed the need to return to a familiar job as being more likely to succeed than a new job. Learning a new job and getting to know new colleagues were deemed more difficult and having a sense of familiar increased participant's confidence. Many participants faced difficulty as their workplace had moved on in the time they had been off work (approx.

one year) and colleagues had changed. Jobs had also changed but more importantly colleague relationships did not have the history they had previously had. Working with new people put more stress on participants, as they didn't know how to approach new colleagues. Managers had also changed and this made it feel like participants had to start from scratch. Some participants had difficulty adapting to change such as changed shift patterns, services where jobs had become bigger with more pressure and where duties were different. Coping with changes to plans resulted for some in stress and headaches. Three participants lost their job after returning and three took medical retirement. This set them back leaving them feeling like everything was declining despite their efforts. Some participants tried work retraining and went on work placements with varying degrees of success. Surprisingly though there was no set return to work option route and all participants experienced different return to work options including the above and finding themselves jobs on the open market, job coaching, voluntary work, sheltered employment, the Workstep scheme (for people with any type of disability which helps get back into work), Workbridge, Work solutions (for people who are long term unemployed) and the Shaw trust (a voluntary, charitable organisation).

Feelings of success

'Feelings of success' were experienced by participants and explained as a factor in their return to work. Many participants described a feeling of success or achievement when their return to work goal was achieved and the relief when they did return and wanting to congratulate themselves as their perception of their job was very much part of who they were. They explained feeling good by earning their own way and valued. Similarly a few participants described feeling like they were made whole again when they returned to work and the relief was great that accompanied that feeling. They also enjoyed the recognition of having their job and getting back to doing a large degree of what they did before and saw this as important. They reported feeling better when working and having increased self-esteem. A few participants recognised changes in their self-awareness recognising that they weren't as sharp, bright and quick as before their injury and understanding that the difficulties they were having were due to their illness. Realisation of what they were capable of helped to establish that part time working was best and trying within their capabilities, not trying to do everything, nor taking on too much. They recognised that they needed to live their lives with just a bit of support around them.

Appendix 21 Phase two descriptive summary

A general situated structure of return to paid work following a brain injury

The intention of this study was to explore the phenomenon return to paid work as expressed by 11 employers of individuals following a brain injury. A general description of this structure is presented below and has been devised following careful reflection of all of the employer's lived experience narratives. It does more than summarise one employer participant's experience and provides a comparison of each individual's idiographic portrait. The summary has been prepared to identify the range of the lived experiences and the perceptions of the researcher, whilst forming the general structure return to paid work following a brain injury. Wertz's (1985) study provided a useful template for presenting the structure in an organised and coherent way. The summary is presented using the six emerging themes following thematic analysis of the 50 meaning units established from participant's interview transcripts. The six themes presented below are: supporting employees to cope with loss and adjustment, providing practical and emotional support to employees, facing challenges, learnt insight, providing rehabilitation, awareness of ongoing employee difficulties.

Please note that the order of the following themes has been rearranged to improve reader presentation in chapter 5.

1. Supporting employees to cope with loss and adjustment

Employers described early post injury fear and anxiety experienced by their employees following their brain injury. Employees had financial worries due to extended sick leave and family commitments. This fear was worse for self-employed injured people as they had to strike a balance of having to go back to work and having to monitor their own health and how much they were able to do. It appears that some people following a brain injury go back to work before they should due to these fears and because they have lost confidence and some ability to make decisions.

Employer's described factors influencing early post injury adjustment as employee's anxiety about returning home, what was going to happen, how their injury would affect their life, not knowing who they were any more and trying to get over their loss. Some employees described to employers' feelings of shame and embarrassment, fear of not being recognised, not being able to speak properly or read or remember quickly. Some employers facilitated adjustment by assigning a member of staff to provide "pretend work" to allow the employee to gauge how much they could remember, their work speed and to allow some trial of their previous work.

Drive to return to work varied for injured employees due to the following factors: some felt it important to be able to do work for their own sanity, to prove to themselves that

they still had the capability and not to be defeated and that their injury had not beaten them. Some employees had to return to work instantly as they couldn't afford to be off, whilst others had no financial concerns and were paid for twelve months' full pay when on sick leave.

Employees were described as preferring to have some feeling of control to their return. Employers described the importance of an employee accepting their disability and how this acceptance positively affected their ability to do and enjoy their job. In their experience this involved accepting a changed job role such as regrading within the organisation or management responsibility being removed.

2. Providing practical and emotional support to employees

Employers described early support that they provided as remote colleague support before return planning began and six to eight week progress reviews either in the workplace or at home. Employers described the important aspects about employee early support as ensuring phased planning took place at each review meeting, instilling confidence in the manager and not allowing the employee to feel under pressure to achieve anything outside of their comfort zone, to provide a supportive environment that allowed space and time and to plan review meetings that helped to understand company's policy on helping people back to work after an injury. Employers felt it important to not just talk from a business point of view but to understand the types of problems employees were having and to try to have only one direct contact with the employee to prevent confusion. Employers generally avoided contact for the first month until they had an idea about the severity of the condition and the longer-term prognosis. Direct employer support varied and included: looking at flexible options to overcome employee difficulties, reducing working hours to reduce stress, providing support with specific tasks i.e. lesson planning, reducing pressure, providing feedback of progress to support employee confidence and setting ground rules for colleagues before the employee returned.

3. Learnt insight

Employers described factors that were helpful in relation to return to work as not applying pressure to employees, taking as much time as they needed to return, gradually building up working hours, and the line manager really knowing the employee and keeping in touch with any occupational or medical advice. Employers explained that at times they had thought employees would never make it back to full time work only to be pleasantly surprised at their achievements. Employers described a respect of employees as they had observed first-hand how hard they had had to work and adapt to be able to work again and how often that was not appreciated by wider colleagues. One employer cried when they realised the employee's courage and how fragile the return had been. Others described the observed benefits to employees as feeling valued although also the

return could increase fellow workers workloads which would not have been there pre injury. It was thought that colleagues behaved more positively where they were apprised of what was actually happening and that they had more admiration for the employee and goodwill. Employers saw the following outcomes of injured employees returning: increased confidence, a positive sense of their own wellbeing, sense of pride in what they are doing and more valued. An advantage of employing a person following a brain injury was described by one employer as useful as they had some understanding of being a disabled person.

4. Providing rehabilitation

Employers described work rehabilitation starting with early contact for some by text, some whilst employees were on sick leave by monthly meetings, some via relatives in relation to hospital progress, some from occupational health to arrange meetings to look at the return to work plan. Early rehabilitation was described by employers as often starting with using public transport, making travel arrangements or via volunteering. Some employees started with gentle rehabilitation programmes of one hour for one day a week or started off with travelling into work having lunch and a chat with the line manager then travelling home. Generally goals were agreed mutually. A very gradual phased increase in hours worked was described as the most common with some who returned too quickly to full time work experiencing failure and decrease in confidence. Some employers provided “mock up scenarios” at home in the first instance which supported employees progress without them having to work in the office with additional distractions such as phones and colleagues talking and this prepared them for return. Line manager support was described as essential to keep control of the employee’s workload and their rehabilitation. In addition employers recommended that it was important to build employees confidence before introducing new challenges. Planning to return was described as very detailed and could involve employees devising their own timetable in conjunction with HR and occupational health. It was explained that where possible negotiation with occupational health was better as opposed to line manager and then relayed to the line manager and colleagues. It was also felt important by employers to keep colleagues informed about what work to expect from the brain-injured employee. Time taken to return to full time work varied and employers recommended a very gradual return as being more effective. Progress to increase hours however was made more difficult when trying to get new employees off benefits in relation to how many hours they could work without losing benefits.

5. Awareness of ongoing employee difficulties

Employers described ongoing employee difficulties they observed as: fatigue, driving problems, self-doubt and ongoing brain injury disabilities.

Fatigue was described as the most common difficulty and as happening very quickly and varying day to day. Fatigue presented itself as an inability to lift things, changed speech in relation to starting a sentence and not finishing it or employees reporting that after work they would sleep 16 hours. Travelling to work especially involving commuting made fatigue worse. Most employees were unable to drive post injury due to post injury epilepsy or surgery but those that could drive had reduced confidence. In addition, some employees doubted themselves due to reduced confidence about the way they would present to others. Brain injury consequences such as: reduced memory, reduced vision, poor attention, reduced tolerance, inflexibility, slow mental processing, ongoing headaches, social withdrawal, limited insight and difficulty writing. All of these difficulties were made worse where colleagues did not understand that the difficulties were associated with the brain injury.

6. Facing challenges

Employers expressed concern that they were helping employees to return to work after a brain injury but had no knowledge of it and it was often following a situation that they learnt more about the problems people experience after an injury. Due to patient confidentiality employers were often unaware of serious issues such as epilepsy until they witnessed an employee having a seizure in the work place. They felt unsupported as there was a lack of medical, psychological and psychiatric support and that the only information they had was often from a General Practitioner or employee stating they were fit to work again. They expressed frustration with General Practitioners as often they were told what the illness was but had no further detail about how to help the employee. In particular the Fit note was introduced and explained by employers as being there to help but in their experience a General Practitioner would tick that an employee was fit for work but would offer no suggestions how to make that happen or how to offer support which would have been useful to the employer. Employers described being surprised at how early employees returned to work only to experience problems and expressed concern at how their lack of knowledge/information could affect work place health and safety and perhaps work decisions being made too early for the employee. Workplace tension was highlighted by four employers in relation to employees struggling to reassert their role on returning to work, anger being displaced towards colleagues, frustration and misunderstandings happening due to communication problems. Challenges in relation to employee's benefits existed and caused employees anxiety. Employees requested that they could not work over a certain amounts of hours, as it would affect their disability allowance. Employers were required to clarify this and manage the fact that when employees were on disability allowance it only allowed them to work eleven and a quarter hours a week and if required employees could work the additional hours on a voluntary basis but contracts had to be accurate. One employer described having to take an employee through competence proceedings due to serious memory problems. Employers described observing and having to manage colleague reactions, as often

colleagues were supportive on initial return but quickly expect employees to do a full job and could change attitudes if they perceived employees were not doing their job effectively. Employers described ill health termination as a process ranging between 6 months to two years that they used where the employee would no longer be able to do their job due to their level of recovery not being enough to be able to do their job and that this involved a detailed medical report about their potential recovery.

Appendix 22 Dissemination plan of PhD findings from 2010 to 2016

The following dissemination activity and achievements have taken place throughout my PhD research from 2010 to date. Please note that text has been **bolded to highlight non-academic dissemination activity and achievements**.

Year	Dissemination activity	Dissemination achieved
2010	• Presentation of the research proposal and ethical considerations to the National Research Ethics Committee, Nottingham. • Applied to the United Kingdom Occupational Therapy Research Foundation (UKOTRF) for a £10, 000 research grant from the Elizabeth Casson Trust.	• Disseminated and defended my proposal, methodology and ethical approach, to gain favourable Ethical opinion to start data collection. • Informed the UKOTRF, College of Occupational Therapists (COT) and the Elizabeth Casson Trust about my research, and my search for back fill funding to progress it. My application was unsuccessful; however feedback stated that my bid rated 2nd and recommended reapplication.
2011	• Applied to the UKOTRF for a £10, 000 research grant from Irwin Mitchell Solicitors. • **Interviewed by BBC Northampton about the UKOTRF Irwin Mitchell Research award and my PhD research.**	• Won the UKOTRF Irwin Mitchell Research Award for (2011-2013). Dissemination progressed as I presented my research to an international academic and practice audience at the National COT conference when collecting the award. • **Regional and public dissemination progressed about my research, reaching some potential participants, brain injury service managers and Headway UK who offered support and requested more information about my research.**
2012	• Abstract submitted to the International Bran Injury Association's (IBIA) 9th World Congress on Brain Injury.	• Invited to present a poster presentation of my phase one findings. Dissemination progressed to an international academic and practice audience: Beaulieu K. The return to paid work of individuals following a brain injury. (Poster presentation). *The International Bran Injury Association's 9th World Congress on Brain Injury, Edinburgh, UK, March 2012.*

	• Abstract submitted to the COT National Annual Conference.	• Invited to present a paper presentation of my phase one findings. Dissemination progressed predominantly to a therapy practice audience: Beaulieu K. The return to paid work of individuals following a brain injury. (Paper presentation). *College of Occupational Therapy Annual Conference, Glasgow, UK, June 2012.*
	• Transfer of registration presentation.	• Dissemination of my phase one findings to a large group of multi professional nursing and allied health professional practice, teaching and research colleagues at the University of Northampton.
2013	• Provided a National Research Ethics Report, Nottingham.	• Dissemination of phase one findings and phase two recruitment progress. Acknowledgement to continue my research.
	• **Invitation from the COT Specialist Section Neurological Practice to contribute and consult on the UK Acquired brain injury guide for occupational therapists.**	• **Dissemination progress made as I was able to add return to paid work as a core area of practice for the first time in this practice publication, and be acknowledged in this internationally available publication: College of Occupational Therapists (2013) *Acquired brain injury: a guide for occupational therapists.* London: Specialist Section Neurological Practice.**
	• **Organised a regional brain injury conference in collaboration with Irwin Mitchell Solicitors.**	• **Dissemination progress made by delivering an opening paper presentation of my phase one findings to a predominately non-academic, non-medical or therapy audience, of mainly case managers, solicitors, brain injury charity staff and brain injured people: Beaulieu K. Return to work after a brain injury-the lived experience (PhD-phase one) (Paper presentation). *Irwin Mitchell Brain Injury Conference, University of Northampton, May 2013.***

	• Abstract submitted to COT National Annual Conference.	• Dissemination progress made by presenting my phase two findings to an international predominantly practice audience: Beaulieu K. The return to paid work of individuals following a brain injury-phase two. (Paper presentation). *College of Occupational Therapy Annual Conference, Glasgow, UK, June 2013.*
	• Abstract submitted for Annual Post Graduate Research (PGR) conference, University of Northampton.	• Invited to present a paper presentation of my phase two findings to fellow University research students and PhD supervisors: Beaulieu K. The return to paid work of individuals following a brain injury (Paper presentation). *Annual PGR conference, University of Northampton, July 2013.*
	• **UKOTRF Irwin Mitchell Research Award Report submitted to COT (2011-2013).**	• **Dissemination progress made as the report is publically available on the UKOTRF, COT web site to all registered occupational therapists to provide research evidence to assist their practice and to inform local policy.**
	• Draft article (Beaulieu, K. Return to work following a brain injury) submitted to the British Journal of Occupational therapy (BJOT).	• Academic dissemination started, but feedback from reviewers recommended major revisions. Decision made to wait until completion of PhD writing up before preparing for resubmission.
2014	• **Invitation to present PhD findings to the Nottingham Traumatic Brain Injury Regional Special Interest Group.**	• **Dissemination progress made by presenting and exploring my findings with a regional multi professional practice audience from both the private and public sector. This was part of a review of their regional practice services and of local policy. This also provided future collaborative research opportunities.**
	• Abstract submitted to the World Federation of Occupational Therapists 16th Congress conference.	• Dissemination progress made by presenting my findings to an international practice and research audience: Beaulieu K. The

		return to paid work of individuals following a brain injury (Paper presentation). *World Federation of Occupational Therapists 16th Congress, Yokohama, Japan, June 2014.*
2015	• **UKOTRF Irwin Mitchell Research Award requirement to provide a summary of my research key findings.**	• **Dissemination progress made as my summary of key PhD findings was published on the UKOTRF, COT web site for all registered occupational therapists to access and to inform their practice and local policy.**
	• **Invitation to present to Manchester Major Trauma Network at Salford Royal Hospital as part of their regional review of rehabilitation services and policy.**	• **Dissemination progress made by presenting and exploring my findings with a wide regional inter professional audience. This was to assist those present to influence their future local practice and policy. Beaulieu K. Returning to paid work - the lived experience of brain injured individuals and employers. (Invited paper presentation). *Rehabilitation After the Major Trauma Centre Conference, Greater Manchester, UK, May 2015.***
	• Abstract submitted to the Health and Wellbeing through Occupation 3rd International Occupational Science Europe Conference.	• Poster presentation of my PhD findings disseminated. Unfortunately I was unable to attend in person, but my poster was displayed: Beaulieu K. Return to paid work following a brain injury; the lived experience. *Health and Wellbeing through Occupation 3rd International Occupational Science Europe Conference, Bournemouth University, UK, 3-4 September 2015.*
	• **Invitation to present at Irwin Mitchell Solicitors National Rehabilitation conference.**	• **Dissemination progress made by delivering an invited paper presentation of my findings to a national, multi professional audience from both the private and public sector and brain injury charities. This specifically looked at rehabilitation in the community and how it could be improved in future practice. Beaulieu K. The lived experience of return to paid work following a brain injury. (Invited paper presentation).*Rehabilitation – Can it***

		be Achieved in the Community? Hilton Hotel, Birmingham, 19 November 2015. **Following this dissemination activity, the charity Meningitis UK approached me regarding the potential use of my conceptual framework with some of their service users.**
2016	• Abstract submitted to the 11th World Congress on Brain Injury.	• Dissemination progress by presenting my findings to an international brain injury research and practice experienced audience: Beaulieu K. A new conceptual framework to facilitate return to paid work following a brain injury. (Poster presentation). *11th World Congress on Brain Injury, The Hague, Netherlands, March 2-5, 2016.*
	• Abstract submitted to the College of Occupational Therapists 40th Annual Conference.	• Dissemination progress by presenting my findings to an international therapy audience. Beaulieu K. A new conceptual framework to facilitate return to paid work following a brain injury. (Paper presentation). *College of Occupational Therapists 40th Annual Conference, Harrogate, UK, June 28-30, 2016.*

In addition to the above dissemination activity and achievements, as a senior lecturer, I have informed all of my teaching related to my PhD findings to both under and postgraduate students from 2010 to date. The undergraduate teaching has been predominately to occupational therapy students and mental health nurses. The post graduate students have been from all health and social care contexts. This has been to influence their future practice and to pass on the lessons I have learned.

References

Abberley, P. (2002) Work, disability and European social theory. In: Barnes, C., Oliver, M., Barton, L. (eds.) *Disability studies today.* Cambridge: Polity Press. pp.121-138.

Archer, M. (2010) *Conversations about reflexivity*. 1st ed. Oxford: Routledge.

Armstrong, J., McPherson, K. and Nayar, S. (2012) External memory aid training after traumatic brain injury: making it real. *British Journal of Occupational Therapy.* **75**(12), pp.541-548.

Artman, L. and McMahon, B. (2013) Functional limitations in traumatic brain injury and their relationship to job maintenance following work re-entry. *Journal of Vocational Rehabilitation.* **39**, pp.13-21.

Ashley, M., Ashley, J. and Kreber, L. (2012) Remediation of information processing following traumatic brain injury: A community-based rehabilitation approach. *Neurorehabilitation.* **31**, pp.31-39.

Athanasou, J. (2003) Acquired brain injury and return to work in Australia and New Zealand. *Australian Journal of Career Development.* **12**(1), pp.58-65.

Aveyard, H. (2014) *Doing a literature review in health and social care: a practical guide.* 3rd ed. Berkshire: Open University Press.

Baldwin, V., Powell, T. and Lorenc, L. (2011) Factors influencing the uptake of memory compensations: A qualitative analysis. *Neuropsychological Rehabilitation.* **21**(4), pp.484-501.

Balestreri, M., Czosnyka, M., Chatfield, D., Steiner, L., Schmidt, E., Smielewski, P., Matta, B. and Pickard, J. (2004) Predictive value of Glasgow coma scale after brain trauma: change in trend over the past ten years. *Journal of Neurosurgical Psychiatry.* **75**, pp.161-162.

Barnes, C. and Mercer, G. (2005) Disability, work, and welfare: challenging the social exclusion of disabled people. *Work, Employment and Society.* **19**(3), pp.527-545.

Barnes, T. and Holmes, J. (2007) Occupational therapy in vocational rehabilitation: a brief guide to current practice in the UK. *College of Occupational Therapists* [online]. Available from: http://www.cot.org.uk/members/profpractice/quality/VRSSWork.pdf [Accessed 8th January 2010].

Barris, R., Kielhofner, G. and Hawkins Watts, J. (1988) *Occupational therapy in psychosocial practice.* New Jersey: Slack Incorporated.

Beaulieu, K. (2007) Occupational therapists' perceptions and management of aggression with brain injured adults. *British Journal of Occupational Therapy.* **70**(4), pp.1-10.

Becker, C. S. (1992) *Living and relating: an introduction to phenomenology.* London: Sage.

Belle-Isle, L. and Benoit, C. (2014) Addressing health inequities through social inclusion: The role of community organisations. *Action Research.* **12**(2), pp.177-193.

Belmont. A., Agar, N. and Azouvi, P. (2009) Subjective fatigue, mental effort, and attention deficits after severe traumatic brain injury. *Neurorehabilitation and Neural Repair.* **23**, pp.939-944.

Benedictus, M., Spikman, J. and Van der Naalt, J. (2010) Cognitive and behavioral impairment in traumatic brain injury related to outcome and return to work. *Archives of Physical Medicine and Rehabilitation.* **91**, pp.1436-1441.

Benner, P. E. (1994) *Interpretive phenomenology: embodiment, caring, and ethics in health and illness.* London: Sage.

Ben-Yishay, Y., Silver, S., Piasetsky, E. and Rattok, J. (1987) Relationship between employability and vocational outcome after intensive holistic cognitive rehabilitation. *Journal of Head Trauma Rehabilitation.* **2**(1), pp.35-48.

Biderman, D., Daniels-Zide, E., Reyes, A. and Marks, B. (2006) Ego-identity: Can it be reconstituted after a brain injury? *International Journal of Psychology.* **41**(5), pp.355-361.

Björkdahl, A. (2010) The return to work after a neuropsychological programme and prognostic factors for success. *Brain Injury.* **24**(9), pp.1061-1069.

Black, C. and Frost, D. (2011) An independent review of sickness absence. *Department for Work and Pensions* [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181060/health-at-work.pdf [Accessed 1st April 2015].

Black, W. and Living, R. (2004) Volunteerism as an occupation and its relationship to health and wellbeing. *British Journal of Occupational Therapy.* **67**(12), pp.527-532.

Blackwood, K. and Wilson, H. (2009) Guidance and direction: occupational therapy in brain injury rehabilitation. *New Zealand Journal of Occupational Therapy.* **56**(2), pp.4-8.

Blank, A., Harries, P. and Reynolds, F. (2013) The meaning and experience of work in the context of severe and enduring mental health problems: an interpretative phenomenological analysis. *Work.* **45**, pp.299-304.

Bleicher, J. (1980) *Contemporary hermeneutics: hermeneutica as method, philosophy and critique.* London: Routledge.

Blumer, H. (1969) *Symbolic Interactionism: Perspectives and method*. Englewood Cliffs, NJ: Prentice-Hall Inc.

Boake, C., McCauley, S., Pedroza, C., Levin, H., Brown, S. and Brundage, S. (2005) Lost productive work time after mild to moderate traumatic brain injury with and without hospitalization. *Neurosurgery.* **56**(5), pp.994-1003.

Bond, T. (2004) An introduction to the ethical guidelines for counselling and psychotherapy. *Counselling and Psychotherapy Research*. **4**(2), pp.4-9.

Bonneterre, V., Perennou, D., Trovatello, V., Mignot, N., Segal, P., Balducci, F., Laloua, F. and De Gaudemaris, R. (2013) Interest of workplace support for returning to work after a traumatic brain injury: A retrospective study . *Annals of Physical and Rehabilitation Medicine.* **56**, pp.652-662.

Bootes, K. and Chapparo, C. (2010) Difficulties with multitasking on return to work after traumatic brain injury: A critical case study. *Work.* **36**, pp.207-216.

Brocki, J. and Wearden, A. (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health.* **21**(1), pp.87-108.

Bryman, A. (2012) *Social research methods*. 4th ed. Oxford: Oxford University Press.

Bryson-Campbell, M., Shaw, L., O'Brien, J., Holmes, J. and Magalhaes, L. (2013) A scoping review on occupational and self-identity after a brain injury. *Work.* **44**, pp.57-67.

Carroll, E. and Coetzer, R. (2011) Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation.* **21**(3), pp.289-305.

Chamberlain, D. (2005) The experience of surviving traumatic brain injury. *Journal of Advanced Nursing.* **54**(4), pp.407-417.

Charmaz, K. (2014) *Constructing grounded theory.* 2nd ed. London: Sage.

Chartered Society of Physiotherapy (2012) AHP Advisory Fitness for Work Report Pilot. *Chartered Society of Physiotherapy* [online]. Available from: http://www.csp.org.uk/documents/fitness-work-report-2013 [Accessed 1st April 2015].

Christiansen, C., Backman, C., Little, B. and Nguyen, A. (1998) Occupations and well-being: a study of personal projects. *American Journal of Occupational Therapy.* **52**(1), pp.91-100.

Christiansen, C. (1999) Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *The American Journal of Occupational Therapy.* **53**(6), pp.547-558.

Christiansen, C. (2000) Identity, personal projects and happiness: Self construction in everyday action. *Journal of Occupational Science.* **7**(3), pp.98-107.

Clark, F., Parham, D., Carlson, M., Frank, G., Jackson, J., Pierce, D., Wolfe, R. and Zemke, R. (1991) Occupational science: Academic innovation in the service of occupational therapy's future. *American Journal of Occupational Therapy.* **45**(4), pp.300-339.

Clark, F. (1997) Reflections on the human as an occupational being: Biological need, tempo and temporality. *Journal of Occupational Science.* **4**(3), pp.86-92.

Clark, F., Jackson, J. and Carlson, M. (2004) Occupational science, occupational therapy and evidence-based practice: what the well elderly study has taught us. In: Molineux, M. (ed.) *Occupation for Occupational Therapists.* 1st ed. Oxford: Blackwell Publishing. pp.200-218.

Clarke, C. (2009) An introduction to interpretative phenomenological analysis: a useful approach for occupational therapy research. *British Journal of Occupational Therapy.* **72**(1), pp.37-39.

Clouston, T. (2014) Whose occupational balance is it anyway? The challenge of neoliberal capitalism and work-life imbalance. *British Journal of Occupational Therapy.* **77**(10), pp.507-515.

Coetzer, B. (2004) Grief, self-awareness, and psychotherapy following brain injury. *Illness, Crisis and Loss.* **12**(2), pp.171-187.

Coetzer, R. (2006) *Traumatic brain injury rehabilitation: A psychotherapeutic approach to loss and grief.* 1st ed. New York: Nova Biomedical Books.

Coetzer, R. (2008) Holistic neuro-rehabilitation in the community: Is identity a key issue? *Neuropsychological Rehabilitation.* **18**(5/6), pp.766-783.

Cohen, L., Morrison, K. and Manion, L. (2007) *Research methods in education.* 6th ed. London: Routledge.

Colaizzi, P. (1978) Psychological research as the phenomenologist views it. In: Valle, R. and King, M. (eds.) *Existential phenomenological alternatives for psychology.* New York: Oxford University Press. pp.57-71.

College of Occupational Therapists (2008) *The college of occupational therapists vocational rehabilitation strategy.* London: College of Occupational Therapists.

College of Occupational Therapists (2009) *Occupational therapy in vocational rehabilitation: A brief guide to current practice in the UK.* London: College of Occupational Therapists Specialist Section Work.

College of Occupational Therapists (2013) *Acquired brain injury: a guide for occupational therapists.* London: Specialist Section Neurological Practice.

College of Occupational Therapists (2015) Definition of occupation. *College of Occupational Therapists* [online]. Available from: http://www.cot.co.uk/ot-helps-you/what-occupational-therapy [Accessed 3rd February 2015].

Cooper, C. (2013) The impact of the workplace on health. *BMJ*. **347**, f4944.

Corrigan, J., Lineberry, L., Komaroff, E., Langlois, J., Selassie, A. and Wood, K. (2007) Employment after traumatic brain injury: Differences between men and women. *Archives of Physical Medicine and Rehabilitation.* **88**, pp.1400-1409.

Creswell, J. (2009) *Research design; qualitative, quantitative and mixed methods approaches.* 3rd ed. London: Sage.

Cronin-Davis, J., Lang, A. and Molineux, M. (2004) Occupational science: The forensic challenge. In: Molineux, M. (ed.) *Occupation for occupational therapists.* 1st ed. Oxford: Blackwell Publishing. pp.169-179.

Crotty, M. (1996) *Phenomenology and nursing research.* South Melbourne: Churchill Livingstone.

Danchev, D. and Ross, A. (2014) *Research ethics for counsellors, nurses and social workers*. 1st ed. London: Sage.

Davys, D. and Tickle, E. (2008) Social inclusion and valued roles: A supportive framework. *International Journal of Therapy and Rehabilitation.* **15**(8), pp.358-363.

Dawson, D., Schwartz, M., Winocur, G. and Struss, D. (2007) Return to productivity following traumatic brain injury: Cognitive, psychological, physical, spiritual and environmental correlates. *Disability and Rehabilitation.* **29**(4), pp.301-313.

de Haan, H. (1998) "Social Exclusion" An alternative concept for the study of deprivation? *IDS Bulletin.* **29**(1), pp.10-19.

Delmar, C. (2010). "Generalizability" as Recognition: Reflections on a Foundational Problem in Qualitative Research. *Qualitative Studies*, **1**(2): 115-128.

Denscombe, M. (2003) *The good research guide: for small-scale social research projects.* 2nd ed. Maidenhead: Open University Press.

Department for Work and Pensions and the Department of Health and the Health and Safety Executive (2005) Health, work and well-being–Caring for our future. *HM Government* [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/209570/health-and-wellbeing.pdf [Accessed 25 July 2015].

Department for Work and Pensions (2013) Fitness for work: the Government response to 'Health at work – an independent review of sickness absence'. *Department for Work and Pensions* [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181072/health-at-work-gov-response.pdf [Accessed 2nd April 2015].

Department for Work and Pensions (2014a) The disability and health employment strategy - one year on. *Department for Work and Pensions* [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/385038/disability-confident-britain.pdf [Accessed 1st April 2015].

Department of Work and Pensions (2014b) *Disability confident Britain.* London: Department of Work and Pensions.

Department of Health (1999) *National service framework in mental health.* London: HMSO.

Department of Health (2005) The National Service Framework for Long-term Conditions. *Department of Health* [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf [Accessed 1st April 2015].

Department of Health (2012) The National Service Framework to improve mental health and wellbeing. *Department of Health* [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216870/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf [Accessed 1st April 2015].

Dewar, B. and Gracey, F. (2007) "Am not was": Cognitive-behavioural therapy for adjustment and identity change following herpes simplex encephalitis. *Neuropsychological Rehabilitation.* **17**(4/5), pp.602-620.

Disability Discrimination Act (1995) Disability Discrimination Act. *Her Majesty's Stationary Office and Queens's Printer of Acts of Parliament* [online]. Available from: http://www.legislation.gov.uk/ukpga/1995/50/pdfs/ukpga_19950050_en.pdf [Accessed 4th May 2015].

Doctor, J., Castro, J., Temkin, N., Fraser, R. and Machamer, J. (2005) Workers' risk of unemployment after traumatic brain injury: A normed comparison. *Journal of the International Neuropsychological Society.* **11**, pp.747-752.

Dodson, M. (2010) A model to guide the rehabilitation of high functioning employees after mild brain injury. *Work.* **36**, pp.449-457.

Dur, M., Unger, J., Stoffer, M., Dragoi, R., Kautzky-Willer, A., Fialka-Moser, V., Smolen, J. and Stamm, J. (2015) Definitions of occupational balance and their coverage by instruments. *British Journal of Occupational Therapy.* **78**(1), pp.4-15.

Englander, J., Bushnik, T., Oggins, J. and Katznelson, L. (2010) Fatigue after traumatic brain injury: Association with neuroendocrine, sleep, depression and other factors. *Brain Injury.* **24**(12), pp.1379-1388.

Erikson, E. (1980) *Identity and the Life Cycle.* London: W. W. Norton and Company.

Erikson, A., Karlsson, G., Borell, L. and Tham, K. (2007) The lived experience of memory impairment in daily occupation after acquired brain injury. *OTJR: Occupation, Participation and Health.* **27**(3), pp.84-94.

Esbjornsson, E., Skoglund, T., Mitsis, M., Hofgren, C., Larsson, J. and Sunnerhagen, K. (2013) Cognitive impact of traumatic axonal injury and return to work. *Brain Injury.* **27**(5), pp.521-528.

Evans, A. (1987) Definition of occupation as the core concept of occupational therapy. *The American Journal of Occupational Therapy.* **41**(10), pp.627-628.

Fadyl, J. and McPherson, K. (2009) Approaches to vocational rehabilitation after traumatic brain injury: a review of the evidence. *Journal of Head Trauma Rehabilitation.* **24**, pp.195-212.

Faragher, E., Cass, M., Cooper, C. (2005) The relationship between job satisfaction and health: a meta-analysis. *Occup Environ Med*. **62**, pp.105–112.

Finlay, L. (1999) Applying phenomenology in research: Problems, principles and practice. *British Journal of Occupational Therapy.* **62**(7), pp.299-306.

Finlay, L. (2011) *Phenomenology for therapists: researching the lived world.* Chichester: Wiley-Blackwell.

Finlay, L. (2014) Engaging phenomenological analysis. *Qualitative Research in Psychology.* **11**, pp.121-141.

Finlay, L. and Gough, B. (2003) *Reflexivity: a practical guide for researchers in health and social sciences.* 1st ed. Oxford: Blackwell Publishing Company.

Finlay, L. and Ballinger, C. (2006) *Qualitative research for allied health professionals: challenging choices.* Chichester: John Wiley.

Forslund, M., Roe, C., Arango-Lasprilla, J., Sigurdardottir, S. and Andelic, N. (2013) Impact of personal and environmental factors on employment outcome two years after moderate-to-severe traumatic brain injury. *Journal of Rehabilitation Medicine.* **45**, pp.801-807.

Fort, E., Bouffard, E., Charnay, P., Bernard, M., Boisson, D., Laumon, B. and Hours, M. (2011) Return to work following road accidents: factors associated with late work resumption. *Journal of Rehabilitation Medicine.* **43**, pp.283-291.

Franulic, A., Carbonell, C., Pinto, P. and Sepulveda, I. (2004) Psychosocial adjustment and employment outcome 2, 5 and 10 years after traumatic brain injury. *Brain Injury.* **18**(2), pp.119-129.

Fraser, R., Machamer, J., Temkin, N., Dikmen, S. and Doctor, J. (2006) Return to work in traumatic brain injury: A perspective on capacity for job complexity. *Journal of Vocational Rehabilitation.* **25**, pp.141-148.

Friedland, D. and Potts, J. (2014) Return to work following moderate-severe traumatic brain injury: A UK community sample. *Clinical Psychology Forum.* **259**, pp.16-19.

Gadamer, H. (1975) *Truth and Method.* New York: Seabury.

Gamble, D. and Moore, C. (2003) Supported employment: Disparities in vocational rehabilitation outcomes, expenditures and service time for persons with traumatic brain injury. *Journal of Vocational Rehabilitation.* **19**, pp.47-57.

Gelech, J. and Desjardins, M. (2010) I am many: The reconstruction of self following acquired brain injury. *Qualitative Health Research.* **10**, pp.1-13.

Gendreau, A. and de la Sablonniere, R. (2014) The cognitive process of identity reconstruction after the onset of a neurological disability. *Disability and Rehabilitation.* **36**(19), pp.1608-1617.

Ghajar, J. and Ivry, R. (2008) The predictive brain state: Timing deficiency in traumatic brain injury? *Neurorehabilitation Neural Repair.* **22**, pp.217-227.

Gilworth, G., Eyres, S., Carey, A., Bhakta, B. and Tennant, A. (2008) Working with a brain injury: personal experiences of returning to work following a mild or moderate brain injury. *Journal of Rehabilitation Medicine.* **40**, pp.334-339.

Giorgi, A. (1985) *Phenomenology and psychological research.* Pittsburgh: Duquesne University Press.

Giorgi, A. (1988) Validity and reliability from a phenomenological perspective. In: Baker, W. J., Mos, L. P., Rappard, H. V. and Stam, H. J. (eds.) *Recent trends in theoretical psychology.* New York: Springer-Verlag. pp.167-176.

Giorgi, A. (1989) One type of analysis of descriptive data: Procedures involved in following a scientific phenomenological method. *Annual Edition of Methods: A Journal for Human Science.* (**Spring**), pp.39-61.

Giorgi, A. (1992) Description versus interpretation: competing alternative strategies for qualitative research . *Journal of Phenomenological Psychology.* **23**(2), pp.119-135.

Giorgi, A. (1997) The theory, practice and evaluation of the phenomenological method as a qualitative procedure. *Journal of Phenomenological Psychology.* **28**(2), pp.235-260.

Giorgi, A. (2000a) The status of Husserlian phenomenology in caring research. *Scandinavian Journal of Caring Sciences.* **14**(1), pp.3-10.

Giorgi, A. (2000b) Concerning the Application of Phenomenology to Caring Research. *Scandinavian Journal of Caring Science.* **14**, pp.11-15.

Giorgi, A. (2006) Difficulties encountered in the application of the phenomenological method in the social sciences. *Analise Psicologica.* **3**(XXIV), pp.353-361.

Gracey, F., Palmer, S., Rous, B., Psaila, K., Shaw, K., O'Dell, J., Cope, J. and Mohamed, S. (2008) "Feeling part of things": Personal construction of self after brain injury. *Neuropsychological Rehabilitation.* **18**(5/6), pp.627-650.

Grauwmeijer, E., Heijenbrok-Kak, M., Haitsma, I. and Ribbers, G. (2012) A prospective study on employment outcome 3 years after moderate to severe traumatic brain injury. *Archives of Physical Medicine and Rehabilitation.* **39**(June), pp.993-999.

Halbauer, J., Ashford, W., Zeitzer, J., Adamson, L. and Yesavage, J. (2009) Neuropsychiatric diagnosis and management of chronic sequelae of war-related mild to moderate traumatic brain injury. *Journal of Rehabilitation Research & Development.* **46**(6), pp.757-796.

Hammersley, M. and Atkinson, P. (1995) *Ethnography: principles in practice.* 2nd ed. London: Routledge.

Hammond, R., Lennon, S., Walker, M. F., Hoffman, A., Irwin, P. and Lowe, D. (2005) Changing occupational therapy and physiotherapy practice through guidelines and audit in the United Kingdom. *Clinical Rehabilitation.* **9**(4), pp.365-371.

Hammond, M., Keat, R. and Howarth, J. (1991) *Understanding phenomenology.* Oxford: Basil Blackwell.

Hanlon, R., Demery, J., Kuczen, C. and Kelly, J. (2005) Effect of traumatic subarachnoid haemorrhage on neuropsychological profiles and vocational outcome following moderate or severe traumatic brain injury. *Brain Injury.* **19**(4), pp.257-262.

Harradine, P., Winstanley, J., Tate, R., Cameron, I., Baguley, L. and Harris, R. (2004) Severe brain injury in New South Wales: comparable outcomes for rural and urban residents. *Mja.* **181**(3), pp.130-134.

Hart, C. (2005) *Doing a Literature Review: releasing the social science imagination.* London: Sage.

Hawkley, L., Williams, K. and Cacioppo, J. (2011) Responses to ostracism across adulthood. *Scan.* **6**, pp.234-243.

Headway (2009) The Facts. *Headway* [online]. Available from: http://www.headway.org.uk/sitepages.asp?step=4&contentid=1520&navid=159 [Accessed 16th September 2009].

Headway (2014) Welfare benefits and brain injury. *Headway* [online]. Available from: https://www.headway.org.uk/Welfare-benefits.aspx [Accessed 18th October 2014].

Heller, W., Mukherjee, D., Levin, R. and Panko Reis, J. (2006) Characters in contexts: Identity and personality processes that influence individual and family adjustment to brain injury. *Journal of Rehabilitation.* **72**(2), pp.44-49.

Hewitt, J., Evans, J. and Dritschel, B. (2006) Theory driven rehabilitation of executive functioning: Improving planning skills in people with traumatic brain injury through the use of an autobiographical episodic memory cueing procedure. *Neuropsychologia.* **44**, pp.1468-1474.

Hewson, D. (1997) Coping with loss of ability: Good grief or episodic stress responses. *Social Science and Medicine.* **44**(8), pp.1129-1139.

Hocking, C. (2000a) Occupational science: a stock take of accumulated insights. *Journal of Occupational Science.* **7**(2), pp.58-67.

Hocking, C. (2000b) Having and using objects in the Western world. *Journal of Occupational Science.* **7**(3), pp.148-157.

Hocking, C. (2008a) The way we were: Romantic assumptions of pioneering occupational therapists in the United Kingdom. *British Journal of Occupational Therapy.* **71**(4), pp.146-154.

Hocking, C. (2008b) The way we were: Thinking rationally. *British Journal of Occupational Therapy.* **71**(5), pp.185-195.

Hocking, C. (2008c) The way we were: The ascendance of rationalism. *British Journal of Occupational Therapy.* **71**(6), pp.226-232.

Hocking, C. (2009) The challenge of occupation: Describing the things people do. *Journal of Occupational Science.* **16**(3), pp.140-149.

Hofer, H., Grosse Holtforth, M., Frischknecht, E. and Znoj, H. (2010) Fostering adjustment to acquired brain injury by psychotherapeutic interventions: A preliminary study. *Applied Neuropsychology.* **17**, pp.18-26.

Hogg, M. and Vaughan, G. (2005) Self and idenitiy. In: Hogg, M. and Vaughan, G. (eds.) *Social Psychology.* 4th ed. London: Pearson Prentice Hall.

Holloway, I. and Wheeler, S. (1996) *Qualitative research for nurses.* Oxford: Blackwell Science.

Holtslag, H., Post, M., Van der Werken, C. and Linderman, E. (2007) Return to work after major trauma. *Clinical Rehabilitation.* **21**, pp.373-383.

Holzberg, E. (2001) The best practice for gaining and maintaining employment for individuals with traumatic brain injury. *Work.* **16**, pp.245-258.

Hooson, J., Coetzer, R., Stew, G. and Moore, A. (2013) Patients' experience of return to work rehabilitation following traumatic brain injury: A phenomenological study. *Neuropsychological Rehabilitation.* **23**(1), pp.19-44.

Husserl, E. (2001) *The shorter logical investigations.* 1st abridged ed. London: Routledge.

Ineson, R. (2015) Exploring paid employment options with a person with severe learning disabilities and high support needs: An exploratory case study. *British Journal of Occupational Therapy.* **78**(1), pp.58-65.

Israel, M. (2015) *Research ethics and integrity for social scientists*. 2nd ed. London: Sage.

Jakobsen, K. (2004) If work doesn't work: How to enable occupational justice. *Journal of Occupational Science.* **11**(3), pp.125-134.

James. C. (2011) Occupation analysis and occupational rehabilitation. In: Mackenzie, L. and O'Toole, G. (eds.) *Occupation Analysis in Practice.* 1st ed. Chichester: Wiley-Blackwell. pp.232-245.

Johansson, B. and Tornmalm, M. (2012) Working memory training for patients with acquired brain injury: effects in daily life. *Scandinavian Journal of Occupational Therapy.* **19**, pp.176-183.

Johansson, U. and Tham, K. (2006) The meaning of work after acquired brain injury. *The American Journal of Occupational Therapy.* **60**(1), pp.60-69.

Johansson, U. and Bernspang, B. (2003) Life satisfaction related to work re-entry after brain injury: a longitudinal study. *Brain Injury.* **17**(11), pp.991-1002.

Johnson, R. (1998) How do people get back to work after severe head injury? A 10 year follow-up study. *Neuropsychological Rehabilitation.* **8**(1), pp.61-79.

Johnsson, H. and Anderson, L. (1999) Attitudes to work and retirement: Generalisation or diversity? *Scandinavian Journal of Occupational Therapy.* **6**, pp.29-35.

Jones, J., Alexander Haslam, S., Jetten, J., Huw Williams, W., Morris, R. and Saroyan, S. (2011) That which doesn't kill us can make us stronger (and more satisfied with life): The

contribution of personal and social changes to well-being after acquired brain injury. *Psychology and Health.* **26**(3), pp.353-369.

Kendall, E., Muenchberger, H. and Gee, T. (2006) Vocational rehabilitation following traumatic brain injury: A quantitative synthesis of outcome studies. *Journal of Vocational Rehabilitation.* **25**, pp.149-160.

Keyser-Marcus, K., Bricout, J., Wehman, P., Campbell, L., Cifu, D., Englander, J., High, W. and Zafonte, R. (2002) Acute predictors of return to employment after traumatic brain injury: A longitudinal follow-up. *Archives of Physical Medical Rehabilitation.* **83**, pp.635-641.

Kielhofner, G. (1977) Temporal adaptation: a conceptual framework for occupational therapy. *American Journal of Occupational Therapy.* **31**, pp.235-247.

Kielhofner, G. (1992) *Conceptual Foundations of Occupational Therapy.* 1st ed. Philadelphia: F. A. Davis Company.

Kielhofner, G. (1997) *Conceptual foundations of occupational therapy.* 2nd ed. Philadelphia: F.A. Davis Company.

Kielhofner, G. (2002) *Model of human occupation: Theory and application.* 3rd ed. Baltimore: Lippincott Williams and Wilkins.

Kielhofner, G. (2008) Dimensions of doing. In: Kielhofner, G. (ed.) *Model of human occupation: Theory and application.* 4th ed. Baltimore: Lippincott Williams and Wilkins. pp.101-109.

Kielhofner, G. and Burke, J. (1980) A model of human occupation, part 1. Conceptual framework and content. *American Journal of Occupational Therapy.* **34**(9), pp.572-581.

King, N., Crawford, S., Wenden, F., Moss, N., Wade, D. and Caldwell, F. (1997) Measurement of post-traumatic amnesia: How reliable is it? *Journal of Neurology, Neurosurgery and Psychiatry.* **62**, pp.38-42.

Kleiman, S. (2004) Phenomenology: To wonder and search for meanings. *Nurse Researcher.* **11**(4), pp.7-19.

Klinger, L. (2005) Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science.* **12**(1), pp.9-16.

Koch, T. (1995) Interpretive approaches in nursing research-the Influence of Husserl and Heidegger. *Journal of Advanced Nursing.* **21**(5), pp.827-836.

Kreutzer, J., Marwitz, J., Walker, W., Sander, A., Sherer, M., Bogner, J., Fraser, R. and Bushnik, T. (2003) Moderating factors in return to work and job stability after traumatic brain injury. *Journal of Head Trauma Rehabilitation.* **18**(2), pp.128-138.

Kubler-Ross, E. and Kessler, D. (2005) *On grief and grieving: Finding the meaning of grief through the five stages of loss.* London: Scribner.

Kubler-Ross, E. and Kessler, D. (2014) *Life lessons: How our mortality can teach us about life and living.* London: Simon and Schuster.

Laliberte Rudman, D. (2002) Linking occupation and identity: Lessons learned through qualitative exploration. *Journal of Occupational Science.* **9**, pp.12-19.

Landa-Gonalez, B. (2001) Multicontextual occupational therapy intervention: a case study of traumatic brain injury. *Occupational Therapy International.* **8**(1), pp.49-62.

Lefebvre, H. and Levert, M. (2006) Sudden and unexpected health situation: from suffering to resilience. *Illness, Crisis and Loss.* **14**(4), pp.337-354.

Levack, W., Boland, P., Taylor, W., Siegert, R., Kayes, N., Fadyl, F. and McPherson, K. (2014) Establishing a person-centred framework of self-identity after traumatic brain injury: A grounded theory study to inform measure development. *BMJ Open.* **4**, pp.1-9.

Levack, W., Kayes, N. and Fadyl, J. (2010) Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and Rehabilitation.* **32**(12), pp.986-999.

Levack, W., McPherson, K. and McNaughton, H. (2004) Success in the workplace following traumatic brain injury: are we evaluating what is most important? *Disability and Rehabilitation.* **26**(5), pp.290-298.

Liddle, J., Fleming, J., McKenna, K., Turpin, M., Whitelaw, P. and Allen, S. (2011) Driving and driving cessation after traumatic brain injury: processes and key times of need. *Disability and Rehabilitation.* **33**(25–26), pp.2574-2586.

Liddle, J., Fleming, J., McKenna, K., Turpin, M., Whitelaw, P. and Allen, S. (2012) Adjustment to loss of the driving role following traumatic brain injury: A qualitative exploration with key stakeholders. *Australian Occupational Therapy Journal.* **59**, pp.79-88.

Lopez, K. and Willis, D. (2004) Descriptive versus interpretive phenomenology; Their contributions to nursing knowledge. *Qualitative Health Research.* **14**(5), pp.726-735.

Ludqvist, A. and Samuelson, K. (2012) Return to work after acquired brain injury: A patient perspective. *Brain Injury.* **26**(13-14), pp.1574-1585.

Macaden, A., Chandler, B., Chandler, C. and Berry, A. (2010) Sustaining employment after vocational rehabilitation in acquired brain injury. *Disability and Rehabilitation.* **32**(14), pp.1140-1147.

MacDonald, G. and Leary, M. (2005) Why does social exclusion hurt? The relationship between social and physical pain. *Psychological Bulletin.* **131**(2), pp.202-223.

Machamer, J., Temkin, N., Fraser, R., Doctor, J. and Dikmen, S. (2005) Stability of employment after traumatic brain injury. *Journal of the International Neuropsychological Society.* **11**, pp.807-816.

Mashta, O. (2009) Employers told to tackle work related stress to reduce sickness bill. *BMJ*. **339**: b4607.

Mateer, C. and Sira, C. (2006) Cognitive and emotional consequences of traumatic brain injury: Intervention strategies for vocational Rehabilitation. *Neurorehabilitation.* **21**, pp.315-326.

McClure. J. (2011) The role of causal attributions in public misconceptions about brain injury. *Rehabilitation Psychology.* **56**(2), pp.85-93.

McCrimmon, S. and Oddy, M. (2006) Return to work following moderate-to-severe traumatic brain injury. *Brain Injury.* **20**(10), pp.1037-1046.

McGrath, J. (2004) Beyond restoration to transformation: Positive outcomes in the rehabilitation of acquired brain injury. *Clinical Rehabilitation.* **18**, pp.767-775.

McLaughlin Gray, J. (1997) Application of the phenomenological method to the concept of occupation. *Journal of Occupational Science.* **4**(1), pp.5-17.

McMahon. B., West, S., Shaw, L., Waid-Ebbs, K. and Belongia, L. (2005) Workplace discrimination and traumatic brain injury: The national EEOC ADA research project. *Work.* **25**, pp.67-75.

McNamee, S., Walker, W., Cifu, D. and Wehman, P. (2009) Minimising the effect of traumatic brain injury-related physical sequelae on vocational return. *Journal of Rehabilitation Research and Development.* **46**(6), pp.893-908.

Meara, N.; Schmidt, L.; and Day, J. (1996) Principles and virtues: A foundation for ethical decisions, policies and character. *The Counselling Psychologist*. **24**(1), pp. 4-77.

Mee, J. and Sumsion, T. (2001) Mental health clients confirm the motivating power of occupation. *British Journal of Occupational Therapy.* **64**(3), pp.121-128.

Meier, L., Semmer, N., Gross, S. (2014) The effect of conflict at work on well-being: Depressive symptoms as a vulnerability factor. *Work and Stress*. **28**(1), pp.31–48.

Mental Capacity Act (2005) The Mental Capacity Act. *The Department of Health* [online]. Available from:

http://www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/theweek/chiefexecutivebulletin/DH_4108436 [Accessed 31st January 2010].

Meyer, A. (1922) The philosophy of occupational therapy. *Archives of Occupational Therapy.* **1**, pp.1-10.

Meyer, A. (1977) The philosophy of occupational therapy. *The American Journal of Occupational Therapy.* **31**(10), pp.639-642.

Molineux, M. (2004) *Occupation for occupational therapists.* Oxford: Blackwell Publishing Ltd.

Morse, J. (1992) *Qualitative Health Research.* London: Sage.

Morse, J. (2000) Responding to the cues of suffering. *Health Care for Women International.* **21**, pp.1-9.

Moustakas, C. (1994) *Phenomenological research methods.* London: Sage.

Munoz, J., Farnworth, L., Hamilton, T., Rogers, S., White, J. and Prioletti, G. (2011) Crossing borders in correctional institutions. In: Kronenberg, F., Pollard, N. and Sakellariou, D. (eds.) *Occupational therapies without borders.* 2nd ed. London: Churchill Livingstone Elsevier. pp.235-246.

Myers, M. (2000) Qualitative Research and the Generalizability Question: Standing Firm with Proteus. *The Qualitative Report*, **4** (3/4) [online]. Available from: http://www.nova.edu/ssss/QR/QR4-3/myers.html-[Accessed 18th January 2016].

National Institute for Health and Care Excellence (NICE) (2014) Head Injury Quality Standard. *NICE* [online]. Available from: http://www.nice.org.uk/guidance/qs74 [Accessed 31st March 2015].

Nightingale, E., Soo, C. and Tate, R. (2007) A systematic review of early prognostic factors for return to work after traumatic brain injury. *Brain Impairment.* **6**(2), pp.101-142.

Nimgade, A. and Costello, M. (2003) Return to work for a company president with traumatic brain injury. *Journal of Head Trauma Rehabilitation.* **18**(5), pp.464-467.

Noonan, A. and D'Cruz, K. (2007) Adults who experienced traumatic brain injury described needing to find and accept a new self-identity before they could successfully integrate occupational adaptations. *Australian Occupational Therapy Journal.* **54**(2), pp.158-160.

O'Callaghan, C., Powell, T. and Oyebode, J. (2006) An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychological Rehabilitation.* **16**(5), pp.579-593.

Oliver, M. (1983) *Social Work with Disabled People.* Basingstoke: Macmillan.

Oppermann, J. (2004) Interpreting the meaning individuals ascribe to returning to work after traumatic brain injury: a qualitative approach. *Brain Injury.* **18**(9), pp.941-955.

Ownsworth, T. (2010) A metacognitive contextual approach for facilitating return to work following acquired brain injury: Three descriptive case studies. *Work.* **36**, pp.381-388.

Ownsworth, T. (2014) *Self-identity after brain injury.* 1st ed. London: Psychology Press.

Ownsworth, T. and McKenna, K. (2004) Investigation of factors related to employment outcome following traumatic brain injury: A critical review and conceptual model. *Disability and Rehabilitation.* **26**(13), pp.765-784.

Ownsworth, T., Desbois, J., Grant, E. and Fleming, J. (2006) The associations among self-awareness, emotional well-being, and employment outcome following acquired brain injury: A 12-month longitudinal study. *Rehabilitation Psychology.* **51**(1), pp.50-59.

Pachalska, M., Duncan MacQueen, B., Kaczmarek, B., Wilk-Franczuk, M. and Herman-Sucharska, I. (2011) A case of "borrowed identity syndrome" after severe traumatic brain injury. *Medical Science Monitor.* **17**(2), pp.18-28.

Parks, J., Diaz-Arrastia, R., Gentilello, L. and Shafi, S. (2010) Post injury employment as a surrogate for functional outcomes: A quality indicator for trauma systems. *Baylor University Medical Proceedings.* **23**(4), pp.355-358.

Persinger, M. (1993) Personality changes following brain injury as a grief response to the loss of sense of self, phenomenological themes as indices of local, lability and neurocognitive structuring as psychotherapy. *Psychological Reports.* **72**, pp.1059-1068.

Petrella, L., McColl, M., Krupa, T. and Johnston, J. (2005) Returning to productive activities: perspectives of individuals with long-standing acquired brain injuries. *Brain Injury.* **19**(9), pp.643-655.

Phelan, S. and Kinsella, E. (2009) Occupational identity: Engaging socio-cultural perspectives. *Journal of Occupational Science.* **16**(2), pp.85-91.

Phillips, J. and Radford, K. (2014) Vocational rehabilitation following traumatic brain injury: What is the evidence for clinical practice? *Advances in Clinical Neuroscience and Rehabilitation.* **14**(5), pp.14-16.

Pierce, D. (2014) *Occupational Science for Occupational Therapy.* 1st ed. New Jersey: Slack Incorporated.

Ponsford, J. and Sinclair, K. (2014) Sleep and fatigue following traumatic brain injury. *Psychiatric Clinics of North America.* **37**, pp.77-89.

Ponsford, J., Ziino, C., Parcell, D., Shekleton, J., Roper, M., Redman, J., Phipps-Nelson, J. and Rajaratnam, S. (2012) Fatigue and sleep disturbance following traumatic brain injury-their nature, causes and potential treatments. *Journal of Head Trauma Rehabilitation.* **27**(3), pp.224-233.

Potvin, M., Rouleau, I., Senechal, G. and Giguere, J. (2011) Prospective memory rehabilitation based on visual imagery techniques. *Neuropsychological Rehabilitation.* **21**(6), pp.899-924.

Power, P. and Hershenson, D. (2003) Work adjustment and readjustment of persons with mid-career onset traumatic brain injury. *Brain Injury.* **17**(12), pp.1021-1034.

Radford, K., Phillips, J., Drummond, A., Sach, T., Walker, M., Tyerman, A., Haboubi, N. and Jones, T. (2013) Return to work after traumatic brain injury: Cohort comparison and economic evaluation. *Brain Injury.* **27**(5), pp.507-520.

Ralph, A. and Derbyshire, C. (2013) Survivors of brain injury through the eyes of the public: A systematic review. *Brain Injury.* **27**(13/14), pp.1475-1491.

Randall, C. (2015) Measuring national well-being: Our relationships. *Office for National Statistics* [online]. Available from: http://www.ons.gov.uk/ons/dcp171766_394187.pdf [Accessed 25th July, 2015].

Rapport, L., Coleman Bryer, R. and Hanks, R. (2008) Driving and community integration after traumatic brain injury. *Arch Phys Med Rehab.* **89**, pp.922-929.

Reed, K. D., Hocking, C. S. and Smythe, L. A. (2011) Exploring the meaning of occupation: The case for phenomenology. *Canadian Journal of Occupational Therapy.* **78**(5), pp.303-310.

Reilly, M. (1962) Occupational therapy can be one of the great ideas of 20th century medicine. *American Journal of Occupational Therapy.* **26**, pp.1-9.

Reiners, G. (2012) Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *Research Journal of Nursing Care.* **1**(5), pp.1-3.

Research Governance Framework for Health and Social Care (2001) The Research Governance Framework for Health and Social Care. *The Department of Health* [online]. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008777 [Accessed 31st January, 2010].

Rietdijk, R., Simpson, G., Togher, L., Power, E. and Gillett, L. (2013) An exploratory prospective study of the association between communication skills and employment outcome after severe traumatic brain injury. *Brain Injury.* **27**(7-8), pp.812-818.

Roberts, A. (2014) The meaning of participation in chosen occupations. *In: World Federation of Occupational Therapists (WFOT) 16th Congress: proceedings of a conference, Yokohama, Japan, 2014.*

Ross, J. (2007) *Occupational therapy and vocational rehabilitation.* 1st ed. Chichester: John Wiley and Sons Ltd.

Roundhill, S., Huw Williams, W. and Hughes, J. (2007) The experience of loss following traumatic brain injury: Applying a bereavement model to the process of adjustment. *Qualitative Research in Psychology.* **4**, pp.241-257.

Rubenson, C., Svensson, E., Linddahl, I. and Bjorklund, A. (2007) Experiences of returning to work after acquired brain injury. *Scandinavian Journal of Occupational Therapy.* **14**, pp.205-214.

Rudman, D., Dennhardt, S., Fok, D., Huot, S., Molke, D., Park, A. and Zur, B. (2008) A vision for occupational science: Reflecting on our disciplinary culture. *Journal of Occupational Science.* **15**(3), pp.136-146.

Rudstam, H., Strobel Gower, W. and Cook, L. (2012) Beyond yellow ribbons: Are employers prepared to hire, accommodate and retain returning veterans with disabilities? *Journal of Vocational Rehabilitation.* **36**, pp.87-95.

Russell, W. and Smith, A. (1961) Post traumatic amnesia after closed head injury. *Arch Neurol.* **5**, pp.16-29.

Ryan, T., Sautter, S., Capps, C., Meneese, W. and Barth, J. (1992) Utilising neuropsychological measures to predict vocational outcome in a head trauma population. *Brain Injury.* **6**(2), pp.175-182.

Sabello, M. (2014) "If you can't do it now, you're out the door:" Employees with traumatic brain injury-a case study. *Work.* **48**, pp.373-379.

Sale, P., West, M., Sherron, P. and Wehman, P. (1991) Exploratory analysis of job separations from supported employment for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation.* **6**, pp.1-11.

Saltychev, M., Eskola, M., Tenovou, O. and Laimi, K. (2013) Return to work after traumatic brain injury: Systematic review. *Brain Injury*. **27**(13-14), pp.1516-1527.

Schmitter-Edgecombe, M. and Seelye, A. (2012) Recovery of content and temporal order memory for performed activities following moderate to severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology.* **34**(3), pp.256-268.

Schnieders, J., Willemsen, D. and de Boer, H. (2012) Factors contributing to chronic fatigue after traumatic brain injury. *Journal of Head Trauma Rehabilitation.* **27**(6), pp.404-412.

Schonberger, M., Ponsford, J., Olver, J., Ponsford, M. and Wirtz, M. (2011) Prediction of functional and employment outcome 1 year after traumatic brain injury: A structural equation modelling approach. *Journal of Neurology, Neurosurgery and Psychiatry.* **82**, pp.936-941.

Schonbrun, S., Sales, A. and Kampfe, C. (2007) RSA services and employment outcome in consumers with traumatic brain injury. *Journal of Rehabilitation.* **73**(2), pp.26-31.

School of Health (2008) *School of Health Ethics Guidelines.* Northampton: The University of Northampton.

Schwartz, S., Zamboanga, B., Luyckx, K., Meca, A. and Ritchie, R. (2013) Identity in emerging adulthood: Reviewing the field and looking forward. *Emerging Adulthood*. **1**(2), pp.96-113.

Scott, K., Lloyd, D., Restubog, S. and Zagenczyk, T. (2013) A social exchange-based model of the antecedents of workplace exclusion. *Journal of Applied Psychology.* **98**(1), pp.37-48.

Scottish Intercollegiate Guidelines Network (2009) *Early management of patients with a head injury: A national clinical guideline.* Edinburgh: Healthcare Improvement Scotland.

Shames, J., Treger, I., Ring, H. and Giaquinto, S. (2007) Return to work following traumatic brain injury: Trends and challenges. *Disability and Rehabilitation.* **29**(17), pp.1387-1395.

Shigaki, C., Johnstone, B. and Schopp, L. (2009) Financial and vocational outcomes 2 years after traumatic brain injury. *Disability and Rehabilitation.* **31**(6), pp.484-489.

Silverman, H. J. (1991) *Gadamer and hermeneutics.* New York: Routledge.

Smith, J., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis; theory, method and research.* London: Sage.

Smith, J. (1996) Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health.* **11**(2), pp.261-271.

Soeker, M. (2011) Occupational adaptation: A return to work perspective of persons with mild to moderate brain injury in South Africa. *Journal of Occupational Science.* **18**(1), pp.81-91.

Soeker, M., Van Rensburg, V. and Travill, A. (2012a) Are rehabilitation programmes enabling clients to return to work? Return to work perspectives of individuals with mild to moderate brain injury in South Africa. *Work.* **43**, pp.171-182.

Soeker, M., Van Rensburg, V. and Travill, A. (2012b) Individuals with traumatic brain injuries perceptions and experiences of returning to work in South Africa. *Work.* **42**, pp.589-600.

Soundy, A., Stubbs, B., Freeman, P., Coffee, P. and Roskell, C. (2014) Factors influencing patients' hope in stroke and spinal cord injury: A narrative review. *International Journal of Therapy and Rehabilitation.* **21**(5), pp.210-218.

Spinelli, E. (2005) *The interpreted world: An introduction to phenomenological psychology.* 2nd ed. London: Sage.

Stergiou-Kita, M., Rappolt, S., Kirsh, B. and Shaw, L. (2009) Evaluating work readiness following acquired brain injury: Building a shared understanding. *Canadian Journal of Occupational Therapy.* **76**(4), pp.276-284.

Stergiou-Kita, M., Rappolt, S. and Dawson, D. (2012) Towards developing a guideline for vocational evaluation following traumatic brain injury: The qualitative synthesis of clients' perspectives. *Disability and Rehabilitation.* **34**(3), pp.179-188.

Strauss, A. L. and Corbin, J. M. (1998) *Basics of qualitative research: techniques and procedures for developing grounded theory.* 2nd ed. London: Sage.

Strangleman, T. (2012). Work identity in crisis? Rethinking the problem of attachment and loss at work. *Sociology*. **46**, pp.411-425.

Streubert, H. and Carpenter, D. (2011) *Qualitative research in Nursing: Advancing the Humanistic Imperative*. 5th ed. Philadelphia: Lippincott Williams and Wilkins.

Strong, J. (2006) The associations among self-awareness, emotional well-being, and employment outcome following acquired brain injury; A 12 month longitudinal study. *Rehabilitation Psychology.* **51**(1), pp.50-59.

Sveen, U., Mongs, M., Roe, C., Sandvik, L. and Bautz-Holter, E. (2008) Self-rated competency in activities predicts functioning and participation one year after traumatic brain injury. *Clinical Rehabilitation.* **22**, pp.45-55.

Tabor Connor, L., Wolf, T., Foster, E., Hildebrand, M. and Baum, C. (2014) Participation and engagement in occupation in adults with disabilities. In: Pierce, D. (ed.) *Occupational science for occupational therapy*. 1st ed. New Jersey: Slack Incorporated. pp.107-120.

Taylor, C. and White, S. (2000) *Practising Reflexivity in Health and Welfare*. 1st ed. Buckingham: Open University Press.

Taylor, M.C. (2005) Interviewing. In: Holloway, I. (ed.) *Qualitative Research in Health Care.* 1st ed. Maidenhead: Open University Press. pp.39-55.

Taylor, M. C. (2007) *Evidence-based practice for occupational therapists.* 2nd ed. Oxford: Blackwell Publishing.

Teasdale, G. and Jennett, B. (1974) Assessment of coma and impaired consciousness: a practical scale. *Lancet.* **2**, pp.81-84.

Telford, K., Kralik, D. and Koch, T. (2006) Acceptance and denial: Implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing.* **55**(4), pp.457-464.

Thomas, E., Levack, W. and Taylor, W. (2014) Self-reflective meaning making in troubled times: Change in self-identity after traumatic brain injury. *Qualitative Health Research.* **24**(8), pp.1033-1047.

Townsend, E. and Wilcock, A. (2004) Occupational justice. In: Christiansen, C. and Townsend, E. (eds.) *Introduction to occupation. The art and science of living.* Upper Saddle River, NJ: Prentice Hall.

Tsaousides, A., Warshowsky, T., Ashman, T., Cantor, J., Spielman, L. and Gordon, W. (2009) The relationship between employment-related self-efficacy and quality of life following traumatic brain injury. *Rehabilitation Psychology.* **54**(3), pp.299-305.

Turner, A. (2007) Health through occupation: Beyond the evidence. *Journal of Occupational Science.* **14**(1), pp.9-15.

Turner, B., Fleming, J., Ownsworth, T. and Cornwell, P. (2011) Perceptions of recovery during the early transition phase from hospital to home following acquired brain injury: A journey of discovery. *Neuropsychological Rehabilitation.* **21**(1), pp.64-91.

Tyerman, A. (2012) Vocational rehabilitation after traumatic brain injury: Models and services. *Neurorehabilitation.* **31**, pp.51-62.

Van der Horn, H., Spikman, J., Jacobs, B. and Van der Naalt, J. (2013) Postconcussive complaints, anxiety, and depression related to vocational outcome in minor to severe traumatic brain injury. *Archives of Physical Medicine and Rehabilitation.* **94**, pp.867-874.

Van Kaam, A. (1966) *Existential foundations of psychology.* Pittsburgh: Duquesne University Press.

Van Manen, M. (1990) *Researching lived experience: Human science for an action sensitive pedagogy.* New York: University of New York Press.

Van Velzen, J., Van Bennekom, C., Edelaar, M., Sluiter, J. and Frings-Dresen, M. (2009a) How many people return to work after acquired brain injury? A systematic review. *Brain Injury.* **23**(6), pp.473-488.

Van Velzen, J., Van Bennekom, C., Edelaar, M., Sluiter, J. and Frings-Dresen, M. (2009b) Prognostic factors of return to work after acquired brain injury: A systematic review. *Brain Injury.* **23**(5), pp.385-395.

Van Velzen, J. M., Van Bennekom, C., Van Dormolen, M., Sluiter, J. K. and Frings-Dresen, M. H. W. (2011) Factors influencing return to work experienced by people with acquired brain injury: a qualitative research study. *Disability and Rehabilitation.* **33**(23-24), pp.2237-2246.

Van Velzen, J., Van Bennekom, C., Van Dormolen, M., Sluiter, J. and Frings-Dressen, M. (2012) Return to work after acquired brain injury: What did people experience? *In: The International Bran Injury Association's 9th World Congress on Brain Injury, Edinburgh, 2012.*

Van Velzen, J. M., Van Bennekom, C. A. M., Sluiter, J. K. and Frings-Dresen, M. H. W. (2015) Early vocational rehabilitation after acquired brain injury: A structured and interdisciplinary approach. *Journal of Vocational Rehabilitation.* **42**(1), pp.31-40.

Vanderploeg, R., Donnell, A., Belanger, H. and Curtiss, G. (2014) Consolidation deficits in traumatic brain injury: The core and residual verbal memory defect. *Journal of Clinical and Experimental Neuropsychology.* **36**(1), pp.58-73.

Vandiver, V., Johnson, M. and Christofero-Snider, M. (2003) Supporting employment for adults with acquired brain injury. *Journal of Head Trauma Rehabilitation.* **18**(5), pp.457-463.

Waddell, G. and Burton, A. (2006) Is work good for your health and well-being? *Department for Work and Pensions* [online] Available from: https://www.gov.uk/government/uploads/system/uploads/attachmentdata/file/209510/hwwb-is-work-good-for-you-exec-summ.pdf [Accessed 25th July 2015].

Waite, M. (2013) *Pocket Oxford English Dictionary.* 11th ed. Oxford: Oxford University Press.

Waljas, M., Iverson, G., Lange, R., Liimatainen, S., Hartikainen, K., Dastidar, P., Soimakallio, S. and Ohman, J. (2014) Return to work following mild traumatic brain injury. *Journal of Head Trauma Rehabilitation.* **29**(5), pp.443-450.

Walker, W. C., Marwitz, J. H., Kreutzer, J. S., Hart, T. and Novack, T. A. (2006) Occupational categories and return to work after traumatic brain injury: A multicenter study. *Archives of Physical Medicine and Rehabilitation.* **87**(12), pp.1576-1582.

Webb, C., Wrigley, M., Yoels, W. and Fine, P. (1995) Explaining quality of life for persons with traumatic brain injuries 2 years after injury. *Archives of Physical Medicine and Rehabilitation.* **76**, pp.1113-1119.

Wehman, P., Targett, P., West, M. and Kregel, J. (2005) Productive work and employment for persons with traumatic brain injury. What have we learned after 20 years? *Journal of Head Trauma Rehabilitation.* **20**(2), pp.115-127.

Wertz, F. (1985) Method and findings in a phenomenological psychological study of a complex life event. In: Giorgi, A. (ed.) *Phenomenology and psychological research.* Pittsburgh: Duquesne University Press.

Westhorp, P. (2003) Exploring balance as a concept in occupational science. *Journal of Occupational Science.* **10**(2), pp.99-106.

Whalley Hammell, K. (2008) Reflections on…well-being and occupational rights. *Canadian Journal of Occupational Therapy.* **75**, pp.61-64.

Whalley Hammell, K. (2009) Sacred texts: A sceptical exploration of the assumptions underpinning theories of occupation. *Canadian Journal of Occupational Therapy.* **76**(1), pp.6-13.

Whalley Hammell, K. (2014) Belonging, occupation, and human well-being: An exploration. *Canadian Journal of Occupational Therapy.* **81**(1), pp.40-50.

Whalley Hammell, K. (2015) Participation and occupation: The need for a human rights perspective. *Canadian Journal of Occupational Therapy.* **82**(1), pp.4-8.

White, B., Driver, S. and Warren, A. (2008) Considering resilience in the rehabilitation of people with traumatic disabilities. *Rehabilitation Psychology.* **53**(1), pp.9-17.

Whiteford, G. (2000) Occupational deprivation: global challenges in the new millennium. *British Journal of Occupational Therapy.* **63**(5), pp.200-204.

Wilcock, A. (1991) Occupational science. *British Journal of Occupational Therapy.* **54**(8), pp.297-300.

Wilcock, A. (1998) Occupation for health. *British Journal of Occupational Therapy.* **61**(8), pp.340-345.

Wilcock, A. (1999) Reflections on doing, being and becoming. *Australian Journal of Occupational Therapy.* **46**, pp.1-11.

Wilcock, A. (2001a) Occupation for health: Re-activating the regimen sanitatis. *Journal of Occupational Science.* **8**(3), pp.20-24.

Wilcock, A. (2001b) Occupational science: The key to broadening horizons. *British Journal of Occupational Therapy.* **64**(8), pp.412-417.

Wilcock, A. (2006) *An occupational perspective of health.* New Jersey: Slack.

Wilcock, A. (2007) Occupation and health: Are they one and the same? *Journal of Occupational Science.* **14**(1), pp.3-8.

Wilding, C. and Whiteford, G. (2005) Phenomenological research: An exploration of conceptual, theoretical, and practical issues. *Otjr-Occupation Participation and Health.* **25**(3), pp.98-104.

Williams, W., Cordan, G., Mewse, A., Tonks, J. and Burgess, C. (2010) Self-reported traumatic brain injury in male young offenders: A risk factor for re-offending, poor mental health and violence? *Neuropsychological Rehabilitation.* **20**(6), pp.801-812.

Willmott, C., Ponsford, J., Downing, M. and Carty, M. (2014) Frequency and quality of return to study following traumatic brain Injury. *Journal of Head Trauma Rehabilitation.* **29**(3), pp.248-256.

Wilson, B., Robertson, C. and Mole, J. (2015) *Identity unknown: How acute brain disease can destroy knowledge of oneself and others.* 1st ed. London: Psychology Press.

Winefield, A., Montgomery, B., Gault, U., Muller, J., O'Gorman, J., Reser, J. and Roland, D. (2002) The psychology of work and unemployment in Australia today: An Australian psychological society discussion paper. *Australian Psychologist*. **37**(1), pp.1-9.

Winegardner, J. (2015) Self-identity after brain injury. *Neuropsychological Rehabilitation: An International Journal.* **25**(1), pp.155-157.

Winkler, D., Unsworth, C. and Sloan, S. (2005) Time use following a severe traumatic brain injury. *Journal of Occupational Science.* **12**(2), pp.69-81.

Wojnar, D. and Swanson, K. (2007) Phenomenology; an exploration. *Journal of Holistic Nursing.* **25**, pp.172-180.

World Federation of Occupational Therapists (WFOT) (2006) Position statement on human rights*. WFOT* [online]. Available from: http://www.wfot.org/ResourceCentre.aspx [Accessed 23rd April 2015].

World Federation of Occupational Therapists (WFOT) (2015) Definition of occupation. *WFOT* [online]. Available from: http://www.wfot.org/aboutus/aboutoccupationaltherapy/definitionofoccupationaltherapy.aspx [Accessed 3rd February 2015].

Wortman, C. and Cohen Silver, R. (1989) The myths of coping with loss. *Journal of Consulting and Clinical Psychology.* **57**(3), pp.349-357.

Yeates, G., Gracey, F. and Collicutt Mcgrath, J. (2008) A biopsychosocial deconstruction of "personality change" following acquired brain injury. *Neuropsychological Rehabilitation.* **18**(5/6), pp.566-589.

Yerxa, E., Clark, F., Jackson, J., Parham, D., Pierce, D., Stein, C. and Zemke, R. (1989) An introduction to occupational science, a foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care.* **6**(4), pp.1-17.

Yerxa, E. J. (1991) Seeking a relevant, ethical, and realistic way of knowing for occupational therapy. *American Journal of Occupational Therapy.* **45**(3), pp.199-204.

Yerxa, E. (1998) Health and the human spirit for occupation. *American Journal of Occupational Therapy.* **52**(6), pp.412-418.